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***‘A bridge to normal’*: An explorative study of
Indonesian women’s experiences of heart
disease and attending a phase two cardiac
rehabilitation programme**

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Abstract

Introduction: Although traditionally cardiovascular disease (CVD) is most commonly framed as a male disease, CVD has become the leading cause of death for both men and women globally. The data in Indonesia indicates that since the 1990s CVD has occupied the top ranking as the leading cause of mortality and now constitutes 37% of the total deaths in the country. It is well established that one of the most effective treatments for patients recovering from acute cardiac illness or surgery is cardiac rehabilitation (CR). CR is a multidisciplinary intervention, designed to improve the quality of life for people with CVD and reduce their morbidity and mortality. Although CR benefits both male and female patients equally, research shows that CR utilisation by women remains lower than for men. This thesis aims to gain an understanding of women's experiences of heart disease and their attendance in phase two cardiac rehabilitation programme in Indonesia. In doing so, the feminist theory was used to guide the inquiry and to interpret the findings.

Methods: A feminist-informed qualitative research was carried out in an outpatient CR unit in the National Cardiovascular Centre, Jakarta, Indonesia. Twenty-six women aged between 30 and 67 years old were interviewed between June and September 2016. Following transcription, data were analysed using qualitative framework analysis, and the findings were theoretically interrogated using an intersectional approach to gender.

Findings: The analysis identified four major themes, including: (1) threat to gender identity, (2) saving face in front of family and others, (3) cardiac rehabilitation as a 'bridge to normal', and (4) contextual factors influence women's attendance in CR. Findings showed that heart disease does not only create functional limitations but more importantly, it had a significant impact on women's sense of self. The limitations to carry out normal roles as a mother/wife and to fulfil gendered expectations, particularly doing the household chores and caring for the family, caused the women to feel less useful and thus threatened their sense of self. The participants sought to find a way to maintain their previous identity and status in the family and society. For this reason, women in this study implemented a number of strategies to mitigate disruption - as well as to reconcile themselves - to their changed life situation.

Attending the CR programmes have helped the women in this study to restore themselves, which incorporated both physical restoration and identity/self-restoration. They felt that the CR programme provided them with the opportunity to address, deal with, and cope with the consequences of having CVD, to gain confidence, ultimately, enabling them to regain their previous position within their family and community. In this light, CR has become a bridge for the women to gain competence and knowledge in order to enable them to re-engage with their former live activities, including family, friendship, and employment.

Conclusions: The study highlights the importance of the women's sociocultural and spiritual backgrounds in shaping the way they perceive their gender roles, in the context of suffering from heart disease. This knowledge can assist healthcare professionals to better understand the needs of women and the fit between women's needs and existing CR programme, thereby providing direction for more effective approaches to the CR programme. The findings of this study also emphasise the need for the development of a personalised care plan within the area of CR, so that the CR programme would be more suitable to the need of each woman. Future work to increase CR attendance in Indonesia, therefore, should be both gender- and culturally-sensitive to the needs of the female CVD patients.

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Lay Summary

Heart disease kills more people in the world than any other disease. It kills just as many women as men in Indonesia, but the focus of most research is on the experiences of men who have heart attacks. Cardiac rehabilitation (CR) is an outpatient programme of exercise training, education, and counselling provided for patients recovering from a heart attack, heart surgery, or other heart problems to help them get back to their everyday life. Generally, CR programmes consists of three phases. Phase I – the inpatient phase - begins while the patient is still in the hospital during the acute phase of the illness. Phase II - the outpatient phase - is the period after hospitalisation where the patients participate in a closely monitored programme of exercise training, health education, and counselling. Lastly, phase III is a long-term maintenance programme, which aims to maintain lifestyle changes and patients' physical fitness. Although men and women receive similar benefits of CR, we know that women were less likely than men to participate in the programmes. The most frequently reported reasons for women's non-participation at CR were transportation difficulties and distance to the CR centre. In addition, lack of referral from physicians has also been identified as the critical factor that leads to the absence of women from CR.

The research is designed to gain an understanding of the experiences of women living with heart disease and their attendance in a phase II CR programme in Indonesia. The research was conducted in an outpatient CR unit in Jakarta, Indonesia. Twenty-six women aged between 30 and 67 years old were interviewed to share their experiences.

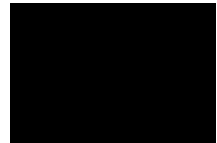
Findings showed that heart disease had a significant impact on many aspects of women's day-to-day life. Since experiencing heart disease, the women were '*not able to do anything like before*' in the sense of performing domestic duties, such as cleaning the house, cooking, nurturing the children, or participating in social activities. They felt that heart disease intertwined with and altered the gendered expectations of caring for others, which they perceived as central to their identity as a woman. The limitations to carry out normal roles as a mother and/or a wife caused the women to feel less useful. For this reason, women employed several strategies to maintain their

status and identity, such as using religious coping, performing small tasks, or hiding their illness from others. Women decided to participate in CR programmes because they wanted to restore themselves, physically, psychologically, and socially so that they would be able to resume their previous roles in the family and society. Being able to share their experience with other patients in the CR unit have been identified as the most significant factor of women's attendance in CR programmes in this research.

Gaining understanding on women's experiences would inform the development CR programmes that are suitable for women so that it can improve women's participation in CR.

Declaration

I declare that this thesis has been composed solely by myself, that the work herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted, in whole or in part, in support of any previous application for any other degree or qualification from this or any other university of institute of learning.



Sutantri

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Abbreviation and Acronyms

AACPR	American Association for Cardiovascular Prevention and Rehabilitation
ACS	Acute Coronary Syndrome
AHA	American Heart Association
AMI	Acute Myocardial Infarction
BACPR	British Association for Cardiovascular Prevention and Rehabilitation
BHF	British Heart Foundation
CABG	Coronary Artery Bypass Graft
CACR	Canadian Association of Cardiac Rehabilitation
CHD	Coronary Heart Disease
CR	Cardiac Rehabilitation
CVD	Cardiovascular Disease
DALY	Disability Adjusted Life Years
DHO	District Health Office
EACPR	European Association of Cardiovascular Prevention and Rehabilitation
ECRIS	European Cardiac Rehabilitation Inventory Survey
ESC	European Society of Cardiology
GBD	Global Burden of Disease
GDP	Gross Domestic Product
HF	Heart Failure
HRQoL	Health-related Quality of Life
IHD	Ischemic Heart Disease
IHME	Institute of Health Metrics and Evaluation
LMIC	Lower-middle Income Country
MHRI	Ministry of Health Republic Indonesia
MI	Myocardial Infarction
MoH	Ministry of Health
NACR	National Audit of Cardiac Rehabilitation
NCC	National Cardiovascular Centre
NCD	Non-communicable Disease
NGO	Non-governmental Organisation
NICE	National Institute for Health and Care Excellence

OOP	Out-of-pocket
PCI	Percutaneous Coronary Intervention
PHO	Provincial Health Office
RCT	Randomised Controlled Trial
UHC	Universal Health Coverage
UK	United Kingdom
USA	United States of America
USPHS	United States Public Health Services
WHO	World Health Organisation
YLD	Years Lived with Disability
YLL	Years of Life Lost

Glossary

Heart disease is “a broad term used to describe a range of diseases that affect the heart, including diseases of heart blood vessels (coronary artery disease), heart rhythm problems (arrhythmias), heart infections and congenital heart disease” (Anderson et al, 2013)

Coronary heart disease is “the most common type of heart disease and its common symptoms are chest pain (angina) and myocardial infarction (MI)” (Anderson et al, 2014)

Cardiac rehabilitation is “the coordinated sum of activities required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental, and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease” (BACPR, 2012)

Phase two CR is a comprehensive outpatient programme that is offered to cardiac patients shortly after their discharge from hospital with duration varying between countries, ranging from 2 weeks to 16 weeks (Bjarnason-Wehrens et al., 2010)

CHAPTER 1: Introduction

1.1 Introduction

This chapter provides some background details relating to a qualitative study of women's experiences of living with heart disease. In particular the factors that influence their attendance in a phase two cardiac rehabilitation (CR) programme in Indonesia, are addressed using feminist-informed qualitative research. In section 1.2, I will explain the reasons and rationale for undertaking this study, and in section 1.3 I state the aims of this thesis in conjunction with the research questions that were set and explored. In the following section (1.4), I present background details of the context of the study. These details include descriptions of: i) the geography of Indonesia, ii) the country's economic profile, iii) its health status, and iv) the nation's healthcare delivery system.

1.2 Background

Although traditionally CVD was commonly seen as being a men's disease (Emslie, 2005, Lockyer and Bury, 2002), cardiovascular disease (CVD) is now reported to have become the primary cause of death among women and men worldwide (Gaziano et al., 2010, World Health Organization, 2015). According to the WHO (2015), approximately 17.5 million people died from CVDs in 2012, which was one-third of all global deaths. Similar fatality-related trends have also been observed in Indonesia over the last two decades, during which time CVD has become the leading cause of mortality in the country. The WHO reported CVD contributed to 37% of the total deaths in Indonesia, exceeding the number of deaths attributed to communicable diseases (WHO, 2015).

Considering the increasing burden of CVD across the globe, primary and secondary prevention initiatives both play a vital role. As a global response to the rise in the numbers of non-communicable disease (NCD) cases, including CVD, the WHO has set a global target; by 2025 to reduce premature deaths attributed to NCDs by 25% (WHO, 2013). A total of 194 member countries of the WHO, including Indonesia, endorsed this global action plan. In its Global Action Plan, the WHO (2013) emphasises the need for rehabilitation, including CR, as a central strategy in: a)

addressing the risk factors of NCDs, b) reducing the consequences of NCDs, c) shortening the patient's hospital stay, and d) improving the quality of life of patients with NCDs.

The WHO (1993) has defined CR as *“the sum of activities required to influence favourably the underlying cause of the disease, as well as to provide the best possible physical, mental, and social conditions, so that the patients may, by their own efforts, preserve or resume when lost, as normal a place as possible in the community”* (p. 1). The primary aim of CR is to restore patients with CVD to a state of good health, as well as enabling them to return to a rewarding role in society (Jolliffe et al., 2001, WHO, 1993). These aims are achieved through a multifaceted and multidisciplinary approach addressing the main modifiable behavioural cardiovascular risk factors (Leon et al., 2005).

Robust evidence demonstrates that CR is effective in: a) reducing mortality rates by up to 25%, b) increasing life expectancy, as well as c) improving the quality of life for people with, or at high risk of developing, CVD (Taylor et al., 2004, Clark et al., 2005, Jolliffe et al., 2001). Despite these recognised benefits, attendance rates at CR programmes are relatively poor globally, with only approximately 15-30% of eligible patients in the USA and Canada participating in CR (Bjarnason-Wehrens et al., 2010, Beswick et al., 2005, Beswick et al., 2004, Grace et al., 2002). Suaya et al. (2007) performed an analysis of Medicare data in the USA and found that only 13.9% of the Medicare recipients hospitalised with Acute Myocardial Infarction (AMI) attended a CR programme. In addition, among patients who underwent Coronary Artery Bypass Graft (CABG) only 31% of those participating in CR.

Several surveys carried out in Europe reported the underutilisation of CR programmes, but also highlighted the difficulties for patients caused by the limited access to such services. The results from the European Cardiac Rehabilitation Inventory Survey (ECRIS) in 2009, which involved 28 countries in Europe, reported the underutilisation of phase two CR programmes. The estimated number of eligible patients who had access to CR ranged from less than 3% (Spain) up to 90% (Lithuania). Over half of the other European countries in the survey estimated the number to be lower than 30% (Bjarnason-Wehrens et al., 2010). The results of the EUROASPIRE IV survey demonstrated that only one-third of the eligible CVD patients

have access to CR services in Europe (Kotseva et al., 2015). A narrative review by Turk-Adawi and Grace (2015) also found that low participation and adherence rates occurred in both high-income and low-income countries; with participation rates lower than 50% in the majority of countries surveyed. Similarly, the dropout rates in the high-income countries ranged from 12-56% and in low-income countries from 55-82%. The most commonly cited barriers identified in the literature include: i) the distance from the programme facility, ii) socio-demographic factors (age, sex, race, and income level), iii) low motivation or low perceived benefits, iv) the lack of physician referral or recommendation, v) transport problems, and vi) social support (Radi et al., 2009, Grace et al., 2014, Humphrey et al., 2014, Menezes et al., 2014, Madan et al., 2014, Goto, 2014, Santos et al., 2014).

Although men and women may receive similar benefits from CR intervention (Todaro et al., 2004, Grace et al., 2008), women were still less likely than men to participate in CR programmes (Samayoa et al., 2014, Allen et al., 2004, Suaya et al., 2007). A meta-analysis conducted by Samayoa et al. (2014) reported CR utilisation among women is still lower than men, accounting for 39% by women and 45% by men. The most frequently reported reasons for women's non-participation at CR were transportation difficulties and the complementary issue of distance to/from the cardiac centre (De Vos et al., 2013). In addition, numerous research studies identified the critical factor that leads to the absence of women from CR: the lack of referral from physicians (Grace et al., 2014, Humphrey et al., 2014, Menezes et al., 2014, Madan et al., 2014, Goto, 2014, Santos et al., 2014). The recent meta-analysis found that only 39.6% of the women were referred to CR, compared to 49.4% of the men (Colella et al., 2015).

Surprisingly, although the knowledge of the women's lower participation in CR has been established for more than two decades, there is still a scarcity of research that utilises a feminist approach to support an investigation into the reasons for this deficit. As shown by Angus et al. (2015), of the 25 studies included in their meta-synthesis that exclusively sampled women, only one was informed by feminist theory. Most studies do not explicitly use gender theory to support their findings and analysis. This omission suggests a research tendency to generalise women's experiences and specific needs, hence obstructing "the complexities of potentially different pathways

of access to programmes” (Angus et al., 2015, p. 1763). Emslie (2005) also highlights the lack of utilisation of gender theories in the study of patients’ experiences with CVD.

There are many studies in health promotion that compare the outcomes of health interventions based on an individual’s sex, but much less frequently is attention paid to the social relations of gender (Gelb et al., 2012). This situation appears to indicate that health system researchers tend to dismiss, or at least ignore, the complex intersections, social relationships of gender, and the different social and cultural locations that shape the possibilities for health in men and women. Schofield et al. (2000) suggested that gender is an essential aspect of health behaviour, as individuals adopt different lifestyles within different contexts, social positions, and relationships. The assertion from Schofield et al. (2000) indicates that any significant changes in individuals’ health behaviour will simultaneously alter gendered interactions, activities, and expectations across social settings. Thus, according to Angus et al. (2015), gender is exceptionally relevant as a lens through which to investigate social processes that underlie access and disparities in clients’ use of health services, including access to CR services.

Gender role expectations of both patients and society have been demonstrated to affect the experience of, and recovery from, illness. Although there has been a considerable change in the women’s roles in the family and society, many women still have to fulfil the primary responsibility for looking after children and housekeeping (Angus, 2001). Furthermore, women are twice as likely as men to assume unpaid caregiving responsibilities at home, such as taking care of the children, the elderly, ill family members, spouses; and often these responsibilities are in addition to other paid work units (United Nations Research Institute for Social Development, 2005). Finn (2001) asserts that caregiving responsibilities negatively affect women’s health and wellbeing, resulting in the disproportionate incidence of various chronic diseases in women.

The literature points out that the lesser participation of women in CR programmes, relative to men, should be studied as an issue of ‘gendered access disparity’ (Angus et al., 2015). Having read some of the available research on women and CR, I initially intended to carry out qualitative research that would aim to explore the factors that influence women’s nonattendance/discontinuation in CR programmes in Indonesia. Such a study would have provided additional information on the factors that contribute

to women's lesser participation in CR programmes. However, during the data collection, it became apparent to me that the majority of the women (>80%) being referred to a CR programme, and who participated in my study, actually enrolled and then continued with their CR attendance. Therefore, I changed the focus of my study to an exploration of women's attendance, focusing on the factors that facilitated their participation, rather than non-attendance or the factors that hindered their participation.

Despite the importance of rehabilitation following a cardiac event, there still appears a dearth of research addressing this area in the Indonesian context. This lack is probably due to the focus of healthcare systems in Indonesia, which still emphasises curative care at the hospital level; thus paying far less attention to the issues of prevention and rehabilitation. Research about CVD and CVD management in Indonesia has heavily emphasised biomedical aspects of the disease; little is known about experiencing the disease at the individual's level, especially women with CVD (Maharani and Tampubolon, 2014, Schröders et al., 2017). There is only a small body of research that describes people's perceptions of health and CVD, and how people attempt to prevent CVD in Indonesia (Dewi et al., 2010, Nur, 2018). However, none of the studies specifically addressed the issues relating to cardiac rehabilitation or women's attendance in Indonesia's CR programmes. For these reasons, I was interested in exploring this phenomenon in depth, in order to provide some insights and evidence in this area, particularly within the Indonesian context. Gaining an understanding of how gender roles influence a person's experience of their illness, as well as clarifying the complex needs of women with CVD, offers more holistic insights into the appropriateness of the CR programmes for women. Hopefully, insights will also be gained into ways to improve the CR programmes, particularly in the Indonesian setting.

Therefore, the key objective of my study was to gain an understanding of women's experiences of living with heart disease and their attendance in phase two level CR programmes in Indonesia. As far as I am aware this study will be the first in this area of research to be conducted in the Indonesian context.

1.3 Research Aim and Questions

As already mentioned, the overall aim of this research study is to gain an understanding of women's experiences of heart disease and their attendance in a phase two cardiac rehabilitation programme in Indonesia.

On this basis, adopting a feminist-informed qualitative approach, I sought to answer the following research questions:

1. How does gender shape women's experience of living with heart disease?
2. How do women decide to participate in a phase two CR programme?
3. What are the contextual factors that influence women's attendance in a phase two CR programme?

1.4 Context of the research

In the following section, I present a brief overview of the research context. I begin with a description of Indonesia's geography and sociodemographics, followed by details of Indonesia's economic profile, health status, and healthcare delivery system.



Figure 1.1 Map of Indonesia

1.4.1 Geography and sociodemographics

Indonesia is the world's fourth most populous country, with an estimated population of over 260 million people (Mboi et al., 2018). The country is also known as the most significant Muslim majority in the world with about 87% of Indonesians also being

Muslims. With more than 17,000 islands situated between the Pacific and the Indian oceans, and between the continents of Asia and Australia, Indonesia is the world's largest archipelago country (Mboi et al., 2018)(see Figure 1.1). The five biggest islands are Sumatera, Java, Kalimantan, Sulawesi, and Papua. There are 34 provinces in Indonesia, comprising of 416 districts and 98 municipalities (Central Bureau of Statistics, 2012). The next lower administrative units are sub-districts and administrative villages.

Aligned with its large number of islands, and their dispersion over a wide area, Indonesia is noted for its cultural diversity. There are more than 300 ethnic groups across Indonesia, although the Javanese dominate in terms of politics and numbers; the Javanese represent over 40% of the nation's total population. With regards to language, there are 724 different languages and dialects in Indonesia. Nevertheless, since Indonesia's independence in 1945, Bahasa Indonesia has been nominated as the official language in the country; it is used in education, media, administration, and business affairs (Mahendradhata et al., 2017).

Considering the small size of Java island, which is less than 7% of Indonesia's total area, more than a half of the Indonesia populations (58%) live on this island. The rest of the population is distributed irregularly across the islands and provinces (Mboi et al., 2018). The Indonesia Demographic and Health Survey (2012) showed that Indonesia's population growth rate has declined in the last three decades, from 1.98% in the 1980s to 1.44% in 2010 (Central Bureau of Statistics et al., 2013). The crude birth rate was reported at 23 births per 1,000 population in 2010.

Indonesia consists of relatively young populations, with a median age of 27 years (Central Bureau of Statistics, 2010). Based on the 2010 census, almost two-thirds of the total population in Indonesia were aged between 15-64 years. As can be seen in Figure 1.2, Indonesia has an expanding type pyramid, which is common for developing countries with high birth and death rates, and relatively short life expectancy. However, the population projections for 2035 forecast that the demographic shift will continue, marked by the increasing number of the aged population, and a smaller fraction of a reproductive-age population (Mahendradhata et al., 2017).

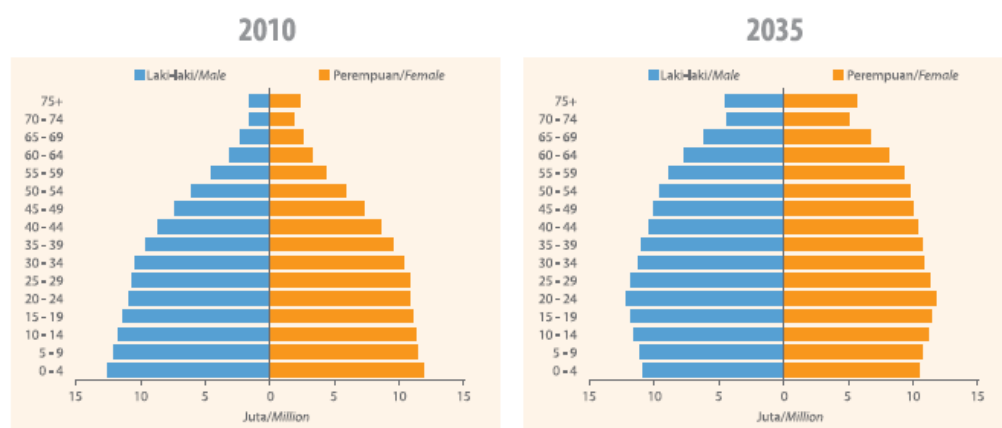


Figure 1.2 Population of Indonesia 2010 and 2035

(Source: Jones (2014), "The 2010-2035 Indonesian Population Projection")

1.4.2 Indonesia's economic profile

Indonesia is a lower-middle income country (LMIC). The annual gross domestic product (GDP) of Indonesia has steadily risen from US\$165.02 billion in the year 2000 to US\$1,015.54 billion in 2017, representing a 5.1% annual GDP growth (World Bank, 2017). Despite the steady decrease in the number of poverty rates, around 31 million of the 260 million population still live below the poverty line. Moreover, 40% of the total households live just slightly above the poverty line with an income of around US\$21 per month.

Historically, the economy of Indonesia was based primarily on the agricultural sector. Over time, there has been a considerable changes in the structure of the Indonesian economy (Elias and Noone, 2011). The processes of industrialisation and urbanisation began in the late 1960s, and as a result the economy of the country has shifted towards the manufacturing sector (see table 1.2). In its attempt to attract more foreign investment, the Indonesian government has focused on upgrading a range of infrastructures, prosecuting corruption case more aggressively, and is taking other steps to improve the regulatory environment. Infrastructure development included the construction of new roads and railways, development of an integrated transportation infrastructure network, and increasing the country's annual electricity generation capacity (Mahendradhata et al., 2017).

Table 1.1 Indonesia – Economic Output by Sector

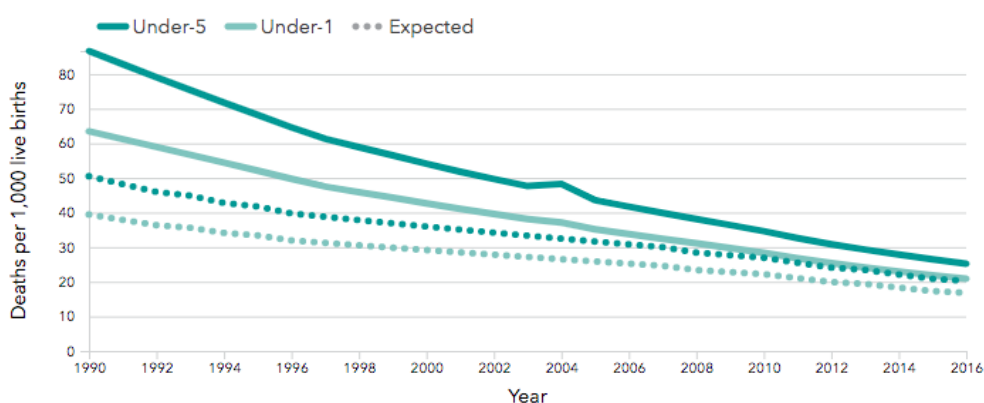
Sector share of GDP, per cent

	1967	1982	1996	1999	2009
Agriculture	51	23	17	20	16
Construction	na	10	10	8	11
Manufacturing	8	13	26	26	27
Mining and utilities	na	17	8	9	11
Services	36	37	40	37	35

Sources: Eas and Noone, 2011 (The Growth and Development of the Indonesian Economy)

1.4.3 Indonesia's health status

Since 1990, Indonesia has made significant improvements to several health issues. For example, there has been a steady growth in life expectancy: from 62 to 69 for male and 66 to 73 years for females. There have also been significant decreases in the rates of infant and maternal mortality (Central Bureau of Statistics et al., 2013). In terms of reduction in child mortality rates, Indonesia has also made considerable progress. The data indicated that the under-five mortality rate decreased significantly from 86.7 to 25.2 per 1000 live births throughout 1990-2016. Furthermore, the infant mortality rate also dropped from 63.5 per 1000 live births in 1990 to 20.9 per 1000 live births in 2016, as illustrated in Figure 1.3 (Institute of Health Metrics and Evaluation [IHME], 2018).

**Figure 1.3 Child mortality 1990-2016**

(Source: Institute of Health Metrics and Evaluation, (IHME, 2018))

The rates of health loss from communicable diseases, such as diarrhoea and tuberculosis, have also decreased significantly since 1990. However, as the

consequence of the advances in economic development in the country, there has been a rapid epidemiological transition of the current and projected disease burden in Indonesia. While the country is still struggling with the burden of communicable disease, Indonesia is facing growing and expensive health threats from heart disease, diabetes, and other non-communicable diseases (Mboi et al., 2018). Based on the findings of the Global Burden of Disease Study (GBD, 2016), stroke and ischemic heart disease have consistently occupied the top ranks of the leading causes of mortality among Indonesians. Figure 1.4 below shows the top 10 leading causes of death in Indonesia and per cent changes from 2007 to 2017.

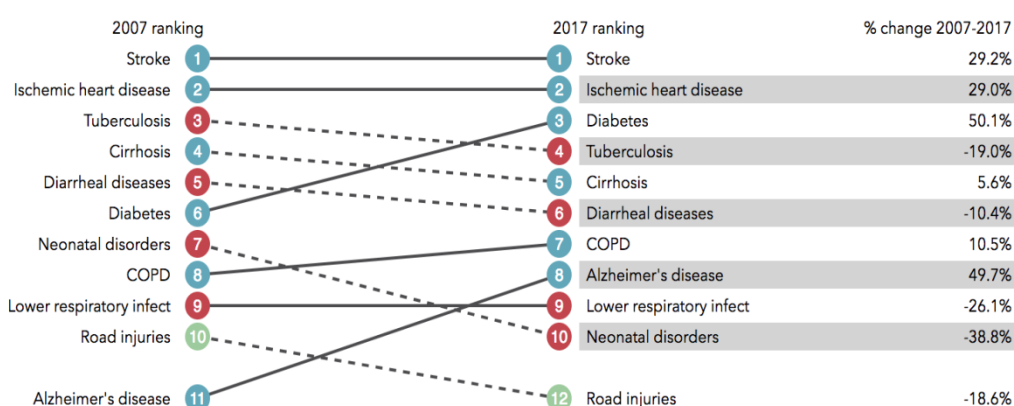


Figure 1.4 Top 10 leading causes of death in Indonesia

(Source: Institute of Health Metrics and Evaluation, 2018)

In 2017, the top three leading causes of premature death in Indonesia were stroke, ischemic heart disease (IHD), and neonatal disorders. The top three causes of disability-adjusted life years (DALYs) lost were stroke, IHD, and diabetes (Figure 1.5). Rates of CVD and diabetes have ballooned over the last two decades, mainly because of unhealthy diets resulting from increased affluence, high blood pressure, and high blood sugar, together with smoking/tobacco-use (Institute of Health Metrics and Evaluation, 2018); all outcomes and examples of the so-called benefits of economic development.

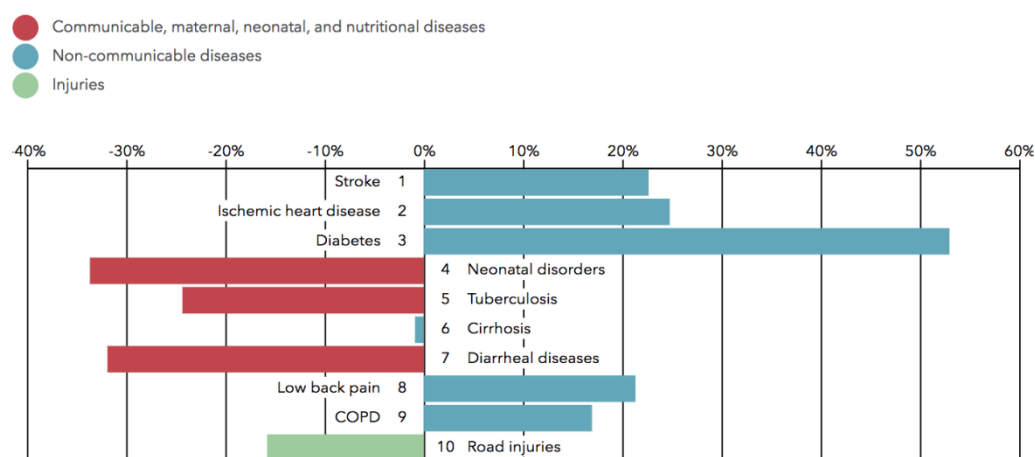


Figure 1.5 Top 10 causes of DALYs in 2017

(Source: Institute of Health Metrics and Evaluation, 2018)

1.4.4 Heart disease in Indonesia

Despite the downward trend of mortality rates attributed to CVD in developed countries in 1990-2010, there has been an upward trend CVD incidence in the developing countries (IHME, 2018). A series of National Health Surveys in Indonesia has demonstrated an increase in the ranking of CVDs as the cause of deaths in the country. While in 1970 CVD was not listed as one the top 10 causes of death, since the 1990s CVD has occupied the top ranking of the leading cause of mortality in the country (Sumartono et al., 2011, Mboi et al., 2018).

In addition to high morbidity and mortality rates, the relatively early onset of CVD among people in developing countries has been associated with the growing social and economic burden of CVD (Maharani and Tampubolon, 2014). Based on the INTERHEART study (2004) conducted in 52 countries, the average age of the patients with AMI in South Asian was 52 years old, 8 years younger than the average age of patients with AMI in Europe and 13 years younger than the North Americans (Yusuf et al., 2004). Research suggests that tobacco use has been the major determinant of these conditions (Sumartono et al., 2011). Smoking prevalence in Indonesia is among the highest in the world, with 64.9% of men and 2.1% of women reported as current smokers (WHO, 2017). However, tobacco control has not become the main political agenda in Indonesia. Indonesia is the only nation in the Asia Pacific that has not ratified the Framework Convention of Tobacco Control (FCTC) (United Nations, 2018), which sets out strategies for government in combating the tobacco

epidemic. In addition, poor diet and lack of physical activity have also been identified as causal risk factors of CVD in Indonesia (Institute of Health Metric and Evaluation, 2018). In response to the significant rise of CVD cases, the government recently issued a new policy (Presidential Decree No. 1, 2017), to improve health promotion and CVD prevention initiatives throughout the country (Mboi et al., 2018). Additional efforts to reduce the high prevalence of NCDs, such as campaigns to promote a healthy lifestyle or development of further legislation are still required to minimise the burden of these preventable risk factors.

In the National Basic Health Survey 2010, CVD prevalence among men and women in Indonesia was as high as 7.2%, with a mortality rate of 31.9% (Ministry of Health Republic Indonesia, 2010). The recent data from WHO (WHO, 2014b) and the George Institute for Global Health (Cardiovascular Division and Health Services Research Centre, 2017) indicated that CVD is the leading cause of death in Indonesia, responsible for 37% of the total deaths. The burden of the disease for 2012 was approximately 18,000 DALYs, of which 17,500 were years of life lost due to premature mortality (YLL) and the remainder due to years of healthy life lost due to disability (YLD) (Cardiovascular Division and Health Services Research Centre, 2017). Above all, stroke has been identified as the leading cause of death in 2012, ending the lives of 328.5 thousand people (representing 21.2% of deaths), followed by ischaemic heart disease which killed 138.4 thousand people (representing 8.9% of deaths) (WHO, 2015). The data shows that diagnosis of CVD is more prevalent among females than males, as well as among patients with lower socioeconomic status (Cardiovascular Division and Health Services Research Centre, 2017). Furthermore, people from the rural area had a higher proportion of CHD compared with the people from the urban area.

Currently, healthcare personnel and services for CVD in Indonesia are still undersupplied and only concentrated in the big cities. The data indicates that between 2015 and 2016, there were approximately 939 registered practicing neurologists, 104 endocrinologists, and 365 cardiologists who were mainly based in Jakarta and large cities (i.e. Surabaya, Bandung, and Yogyakarta) (Cardiovascular Division and Health Services Research Centre, 2017). Based on that number, it means that approximately 1.5 cardiologists are required to serve 1,000,000 people in Indonesia (Mahendradhata et al., 2017). The undersupply of specialised cardiovascular disease health services for large areas of Indonesia point to considerable challenges in the ability of the health

system to implement effective CVD care and treatments. The patients need to deal with longer waiting times and potentially limited access due to undersupply of healthcare services for CVD (Cardiovascular Division and Health Services Research Centre, 2017). The findings from the 2008 Indonesian Family Life Survey reveals nearly 70% of respondents with moderate to high CVD risk, failed to receive any CVD treatment. Accessing services for CVD becomes more problematic in rural areas due to the long distance to the nearest healthcare facilities; thus, the patients cannot receive appropriate treatment in a timely manner.

Despite the benefits of the CR programme, the number of CR services in the country is minimal. Currently, cardiac rehabilitation is mainly a hospital-based programme in Indonesia, with the CR programmes only being implemented in several big city hospitals (Radi et al., 2009).

1.4.5 Healthcare delivery system

1.4.5.1 Organisation

The uneven distribution of the Indonesian population has presented considerable challenges for various aspects of health service provision, such as: i) governance, ii) communication, iii) transportation, and iv) the availability of evenly distributed healthcare services (Mboi et al., 2018). For these reasons, two decades ago the Indonesian government passed law 22 to initiate the process of decentralisation. Following decentralisation reforms in 1999, local and regional governments have greater autonomy to serve their diverse populations. Health services were decentralised to the care and administration of provincial and district governments under the supervision of the Ministry of Home Affairs. The organisation of the health system in Indonesia can be seen in figure 1.6.

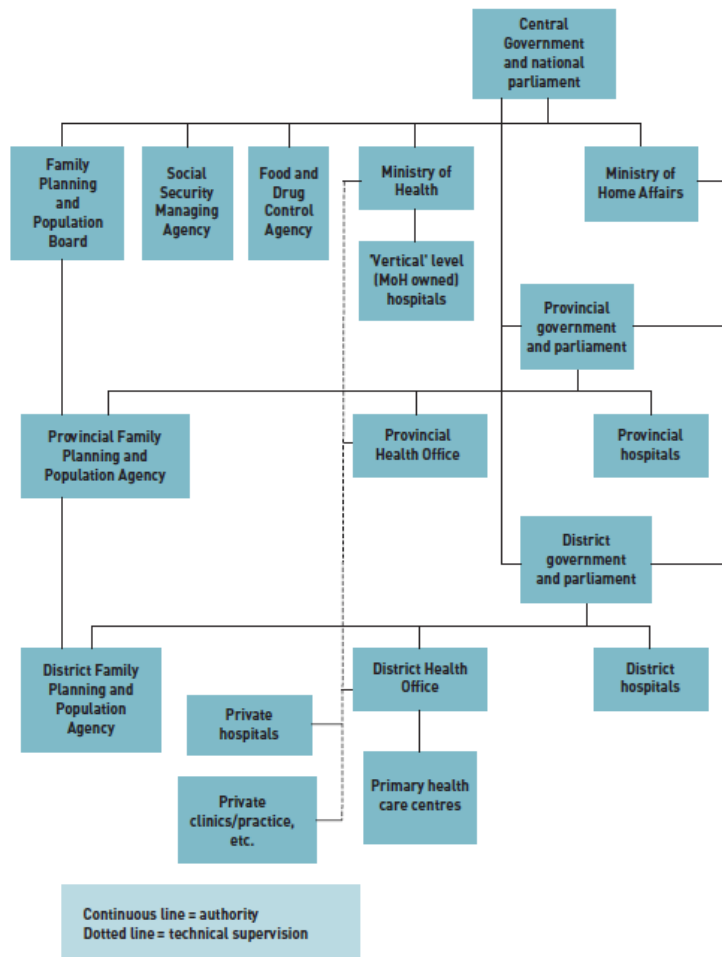


Figure 1.6 Organisation of the health system in Indonesia

(Source: The Republic of Indonesia Health System Review, Mahendradhata et al., 2017)

There are two divisions of health services at the local level: i) provincial and ii) district. Provincial hospitals belong to, and are therefore the responsibility of, the provincial government, while districts hospitals belong to district/municipality governments, with the same proviso. Provincial and district/municipality governments organise health services through the provincial and district health offices. Nevertheless, the relationship between the Ministry of Health, provincial health offices, and district health offices is not hierarchical; meaning that each level has its own commands and area of authority (Mahendradhata et al., 2017).

The demand for health services in Indonesia has increased over the years, following the economic growth in the country. This condition has driven the government to open the health sector for investment, resulting in an increasing number of for-profit private providers. The private sectors consist of hospitals, private and group practices,

midwifery clinics, clinical laboratories, and pharmacies (Mahendradhata et al., 2017). Hospitals in Indonesia are categorised by their facilities and services into Class A, Class B, Class C, and Class D. Based on the data of MoH in 2017, there were a total of 2198 hospitals consisting of 1620 general hospitals and 578 specialised hospitals in Indonesia. Of these, 1334 (60.69%) were in the private sector (MoH, 2018a).

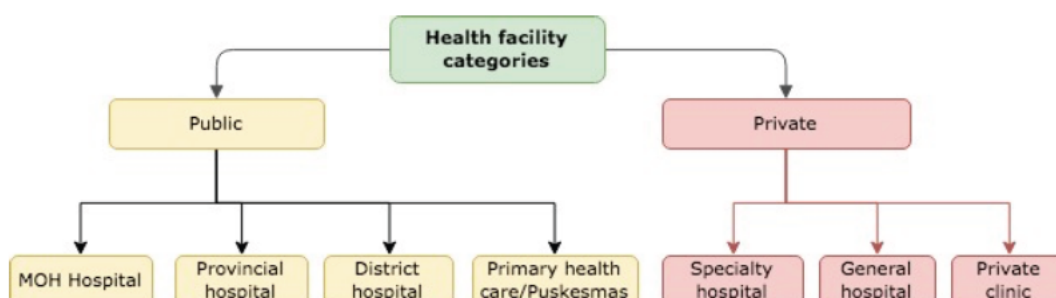


Figure 1.7 Categories of health facilities in Indonesia

1.4.5.2 Human resources

Over the last decade there has been significant growth in the number of health workers in Indonesia, as indicated by the increasing ratio of health workers to population (Mahendradhata et al., 2017). The trends of four different health practitioners' populations in Indonesia throughout 1992-2014 are presented in Table 1.8. The main categories of health care personnel in Indonesia are doctors, nurses, midwives, dentists, pharmacists, clinical psychologists, and other supporting health workers. Although there has been an upward trend for the ratio of physicians per population since 1990, the numbers are still below the ideal ratio recommended by the WHO.

Table 1.8 Health practitioners in Indonesia per 1000 populations

Indicators	1992	2002	2010	2011	2012	2013	2014
Physicians	0.15	0.17	0.37	0.39	0.41	0.43	0.46
Nurses	0.52	0.50	0.67	0.91	0.99	1.16	0.70
Midwives	0.12	0.26	0.41	0.51	0.53	0.55	0.54
Dentists	0.02	0.02	0.04	0.04	0.05	0.05	0.02

Source: MoH database of government employees (http://bppsdmk.kemkes.go.id/nfo_sdmk/)

Between 2000 and 2014, the number of registered physicians increased by approximately 500%, from 21,467 to 129,076 (Paramita et al., 2018). The introduction of a new registration system for physicians in 2010, as well as the number of Indonesia's new medical schools over the last ten years, has driven this massive increase in the number of physicians. Despite the substantial increase in the number, the ratio between physicians and the population in Indonesia is still the lowest among the Asian region countries (Mahendradhata et al., 2017).

As in other countries, in Indonesia nurses and midwives provide the largest health workforce, with a total of 296,876 nurses and 163,541 midwives (MoH, 2018b). However, Indonesia is still experiencing a shortage of nurses and midwives at both hospital and primary care levels (Mahendradhata et al., 2017). World Bank (2014) reported that there is a shortage of 87,874 nurses and 15,311 midwives at the hospital level. Corresponding with the physician-population ratio, the ratio of nurses to population is also still the lowest among countries in the Asian region.

There is also an apparent inequitable distribution of health workers in Indonesia, following the pattern of the uneven population distribution across the archipelago. Figure 1.8 highlights this biased distribution of hospitals and physicians in Indonesia. The majority of physicians, nurses, and midwives are concentrated in Java island, particularly Java and Sumatra.

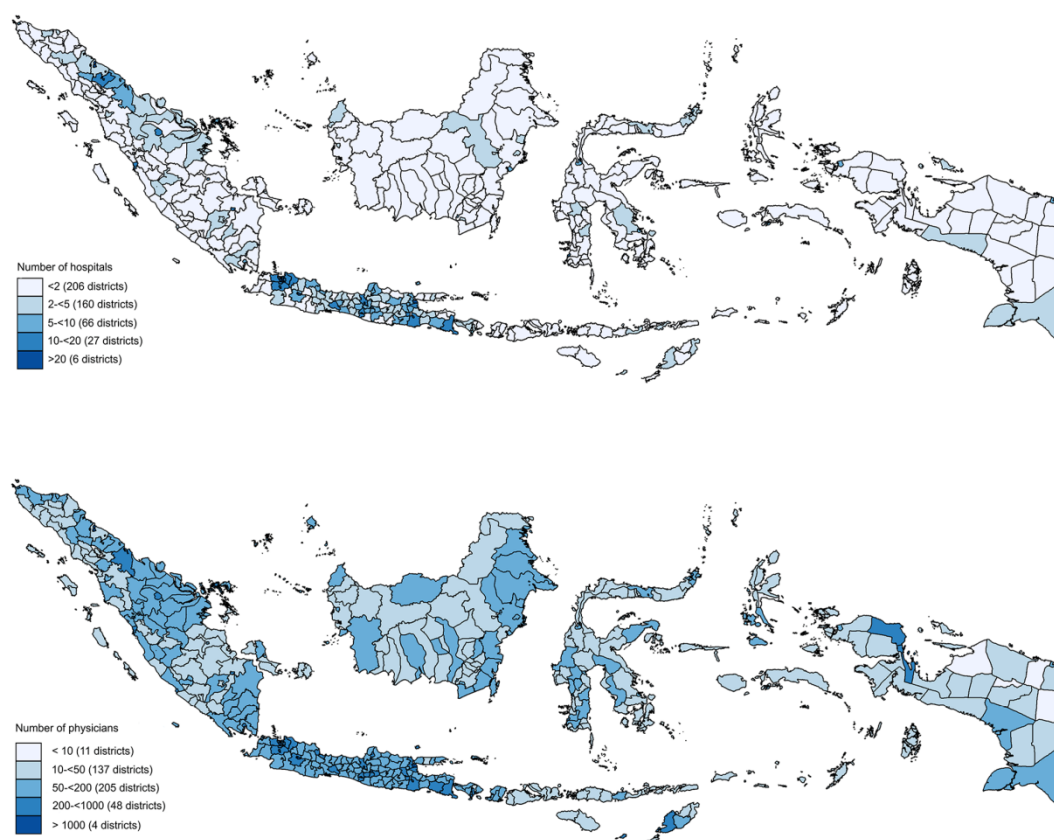


Figure 1.8 Number of hospitals and physicians across the district in 2008

(Source: Maharan and Tampubon (2014) p. 3)

1.4.5.3 Health financing

Total health expenditures have registered a dramatic increase of over 200% since 2000, with private expenditure accounting for two-thirds of all health spending, often in the form of out-of-pocket expenditure (OOP) (Mahendradhata et al., 2017). In response to this issue, in 2004, the government started to introduce social insurance schemes for health care, targeted at and designed mainly for the poor, such as *Askeskin* and *Jamkesmas*. At the beginning of 2014, all social insurance programmes in Indonesia, such as *Jamkesmas* and *Jamkesda* (a state-provided insurance system for the poor), *Askes* (for civil servants), and *Jamsostek* (the social security scheme) were merged into a single-payer universal health coverage (UHC) model, known as *Jaminan Kesehatan Nasional* (JKN/National Health Insurance Scheme). This scheme is administered by *Badan Penyelenggara Jaminan Sosial Kesehatan* (BPJS/Social Insurance Administration Organisation). Under the JKN scheme, all Indonesian citizens will be able to access a comprehensive level of care, both outpatient and inpatient care from the primary level up to tertiary hospital settings. Universal health

coverage is expected to be achieved by 2019 when 95% of the Indonesian population are enrolled in and covered by the insurance scheme. The data from July 2017 showed that JKN had agreements with 26,000 health providers across 34 provinces in Indonesia with a total membership of 180.7 million or 68% of Indonesia's population (Mboi et al., 2018).

1.5 Structure of the thesis

This thesis includes seven chapters.

Chapter 1 provides some background information about the research project. The research aim and questions with an outline of the development of my interest in studying women's attendance in the cardiac rehabilitation programme have been presented. This chapter also provides the general background information relevant to the study context of Indonesia; focusing on the nation's geography and population, economic profile, health status, and healthcare delivery system.

Chapter 2 provides a review of the literature on women and cardiac rehabilitation, as well as the theoretical perspective underpinning this thesis.

Chapter 3 presents the research design and methods employed in the research to answer the research questions, as well as the philosophical assumptions underpinning this study. Points relating to ethical issues, reflexivity, and trustworthiness are also presented.

Chapters 4 and 5 present the findings of the research study. In chapter 4 I present themes and subthemes identified from analysing the data related to women's experiences living with heart disease, while in chapter 5 I present themes and subthemes related to women's attendance in CR programmes.

Chapter 6 provides an overarching discussion of the findings, by highlighting key findings and examining the findings regarding the relevant literature.

Chapter 7 presents the conclusions of this PhD research with a discussion focused on the limitations of the study, as well as implications and recommendations for practice, future research, and policy.

CHAPTER 2: Literature Review and Theoretical Perspective

2.1 Introduction

In the previous chapter, I described the background of my study and also presented some information about the study's context: Indonesia. Charmaz (2014) noted that a research project's literature review determines the research questions as well as 'setting the stage' for the data interpretation process presented in the later chapters. Therefore, this literature review focuses on key aspects of this study and is presented in a narrative format.

Gender differences in CVD treatment have just started to gain attention in Indonesia; it was only in 2015 that the Indonesian Heart Association developed a guideline for CVD treatment and prevention written specifically for women (Indonesian Heart Association, 2015). Overall, this literature review will provide a rationale for the importance of studying gender in the cardiac rehabilitation context, as well as identifying the research question(s).

Specifically, this chapter will be divided into two parts. The first part will present the overview of the literature related to cardiac rehabilitation programmes. The second part of this review chapter will illustrate the theoretical perspectives which provide the basis for this thesis. I start with a brief overview of cardiac rehabilitation programmes, their components and organisation, and the benefits of CR. Following that, I will also describe the key themes reported in the literature on women and cardiac rehabilitation programmes; citations which also cover the facilitators and barriers to CR participation. Finally, in the last part of the review, I provide an overview of the theoretical framework informing this research, starting with the description of feminism in Indonesia, then Western feminism, and lastly the concept of intersectionality.

2.2 Literature search methods

I carried out the literature search mainly on electronic databases, including CINAHL, MEDLINE, PsycINFO, EMBASE, and online search engines, such as PubMed, DiscoverEd, and Google Scholar. Search terms used included 'women', OR 'female',

AND 'cardiac rehabilitation', OR 'secondary prevention', OR 'exercised-based', AND 'myocardial infarction', OR 'cardiovascular disease', OR 'heart attack', OR 'heart disease', AND 'participation', OR 'attendance', OR 'experience(s)' (see Appendix 1 on the example of how search terms were combined). These terms were identified as relevant following a general review of related literature, discussions with supervisors and expert academics in the field. Further, I identified additional sources through manual searching of the reference lists of retrieved articles. Lastly, several guidelines and policies related to cardiac rehabilitation were also included in this review. Therefore, I also used the search term in the Indonesian language to identify studies that were conducted within the Indonesian setting. The literature search was started in 2015 and was regularly updated through the following three years as the popularity of research on women and cardiac rehabilitation continued to grow.

Both English and Indonesian publications are included. Since there is only a limited number of published material available regarding women's participation in cardiac rehabilitation in Indonesia and its surrounding Asian countries, the majority information presented in this literature review is from the UK, North America, Australia, and Europe.

2.3 Cardiac Rehabilitation Programmes

In this section, I begin the review with an examination of the definition, the core components, and benefits of CR programmes. Numerous research studies have clearly demonstrated the benefits of CR programmes, and as such this was not to be the main focus of this literature search.

2.3.1 Definition

CR was initially defined by the WHO (1993) as *"the sum of activities required to influence favourably the underlying cause of the disease, as well as to provide the best possible physical, mental, and social conditions, so that the patients may, by their own efforts, preserve, or resume when lost, as normal a place as possible in the community"*. Goble and Worcester (1999) have altered this definition to embrace the definition set up by both the WHO and the European Society of Cardiology (ESC), as well including the definitions from the US Public Health Services (USPHS):

“CR is the co-ordinated sum of interventions required to ensure the best physical, psychological, and social conditions so that patients with chronic or post-acute CVD may, by their own efforts, preserve or resume optimal functioning in society and, through improved health behaviours, slow or reverse the progression of disease” (Goble and Worcester, 1999, p. 10-11)

The American Heart Association (AHA), in collaboration with the American Association of Cardiovascular and Pulmonary Rehabilitation (AACPR), further expand on these definitions to qualify CR as a ‘coordinated, multifaceted intervention’ that has the potential to hinder or reverse the ‘atherosclerotic processes, thereby reducing morbidity and mortality’ (Leon et al., 2005). For the purpose of this thesis, I use the following definition of the British Association for Cardiovascular Prevention and Rehabilitation (BACPR), as it encompasses the main ideas of CR:

“The coordinated sum of activities required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental, and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease” (BACPR, 2017, p. 1).

2.3.2 Components and organisation of CR

CR facilities offer a wide variety of programmes. A vast majority of the literature identified the importance of a multifaceted and multidisciplinary approach that not only provides exercise training as a single programme.

Along with the exercise-based training, it is highly recommended that CR offers a comprehensive programme, including such services as patient education and psychological intervention (Anderson and Taylor, 2014). It has been suggested that CR programmes should comprise several specific core components targeted to improve patient outcomes by lessening risks of re-infarction, managing symptoms, and promoting a healthy lifestyle (Tod et al., 2002, Balady et al., 2007). According to the secondary prevention guidelines issued by the AHA/American College of Cardiology (ACC), core components of CR should include: a) patient assessment, b) nutritional and physical exercise counselling, c) exercise training, d) weight control management, e) tobacco cessation, f) aggressive coronary risk-factor management

(i.e. blood pressure, lipid, diabetes), and g) psychosocial management (Balady et al., 2007). Meanwhile BACPR (2017) identified six core components of CR, including: a) health behaviour change and education, b) lifestyle risk factor management, c) psychosocial health, d) medical risk management, e) long-term strategies, and f) audit and evaluation.

There are many variations in the organisation and delivery of CR programmes, including the type and intensity of exercise, duration, and programme length (Price et al., 2016). However, with regard to the type of exercise, aerobic endurance exercise have been accepted and incorporated into the CR guidelines of most countries (Price et al., 2016). In terms of the exercise intensity, there are differences between locations. For instance, moderate to higher intensity training programmes have been implemented in CR delivery by countries such as the USA, Canada and several countries in Europe. Whereas, the clinical guidelines throughout the UK, Australasia, France, and Japan have recommended a lower-intensity exercise training, with less focus on resistance training (Price et al., 2016). The organisation of CR also differs with regard to the number of phases of delivery; for instance in the UK and most European countries, CR is divided into four phases (Bethell et al., 2009). Whereas, in the USA, and some other countries, CR consists of three phases, where phases II and III are merged (Taylor et al., 2004). The UK, for instance, currently has a four phase CR model because there is an additional phase between the inpatient and outpatient CR phases (Bethell et al., 2009). Phase II in the UK constitutes the “period of convalescence at home” before the outpatient CR begins (Bethell et al., 2009, p. 271). In Indonesia, CR programmes are divided into three distinct phases and consist of exercise training, educational, and psychological interventions. The overview of the content and structure of each stage in Indonesia’s current CR programme is presented below:

a. Phase I : *inpatient phase*

Phase I is known as the inpatient phase and begins while the patient is still in the hospital during the acute phase of their illness. At this stage, patients are exposed to early mobilisation, which is delivered on an individual basis. Also, formal inpatient education and training programmes often take place during this phase. However, the shorter hospital stay (4-6 days after MI, 5-7 days after CABG, and one day after Percutaneous Coronary Intervention (PCI) makes it exceptionally difficult to carry out

formal inpatient education and training programmes (Taylor et al., 2004, Bjarnason-Wehrens et al., 2010). Therefore, phase I CR is mostly limited to early mobilisation and brief counselling about the nature of the illness, the treatment, risk factor modification, and follow-up planning.

b. Phase II : *early outpatient phase*

Phase II is the early outpatient phase of CR with its duration varying between countries; normally ranging from 2 weeks to 16 weeks after discharge (Bjarnason-Wehrens et al., 2010, Grace et al., 2014). During this period, patients participate in a structured and closely monitored programme of physical activity, psycho-educational activities, nutritional counselling, and other forms of risk factor management. Programmes are usually based in an outpatient clinic, patient's home, or a wing of a hospital or community centre (Balady et al., 2007). The result of the European Cardiac Rehabilitation Inventory Survey (ECRIS) showed that most of the countries in Europe (86%) offer inpatient rehabilitation with a duration of less than 2 weeks (Bjarnason-Wehrens et al., 2010). Some European countries also offer a home-based phase II part of the CR programme, although the number is still far below the inpatient and outpatient programmes (Bjarnason-Wehrens et al., 2010). The content of formal outpatient CR programmes varies widely across different settings. However, exercise training has been identified as the central element of most phase II CR programmes (Bjarnason-Wehrens et al., 2010).

c. Phase III : *long-term maintenance*

Phase III is a long-term maintenance programme in which emphasis is given to physical fitness and additional risk-factor reduction (Bjarnason-Wehrens et al., 2010). The aim of the third phase is to maintain lifestyle changes established in the previous phases. This phase is more varied in content and structure than the early outpatient phase (phase II).

2.3.3 Benefits of participating in CR programmes

CR has proven to be useful and beneficial for patients with a wide range of cardiac conditions, including those who suffered from: a) acute MI, b) have undergone coronary artery bypass graft surgery (CABG) and coronary revascularisation, c) present with stable angina, d) exhibit symptoms of chronic heart failure, e) have undergone heart valve repair or replacement, and f) have received heart and/or lung

transplantations (Goto et al., 2003, Leon et al., 2005, Niebauer et al., 2013, Madan et al., 2014, Grace et al., 2014, Goto, 2014). Secondary prevention programmes have been proven effective to enhance the health outcomes of cardiac patients by lowering the risk of subsequent cardiac events and maintain a certain level of physical functioning (Ades, 2001, Leon et al., 2005, Balady et al., 2007). There has been considerable evidence supporting the effectiveness of exercise-based CR in i) decreasing mortality and readmissions, ii) improving quality of life and iii) exercise tolerance among CVD patients (Clark et al., 2005, NICE, 2013). Based on the strong evidence of its effectiveness, the national and cardiology organisations in the USA and Canada recommend CR as a Class I level A recommendation for patients with CVD (Antman et al., 2004, Leon et al., 2005, Balady et al., 2007). This recommendation for CR has also been supported by many international cardiology societies, such as those from Australia, Europe, New Zealand, and the UK (Oldridge, 2012).

Various studies and meta-analyses have consistently shown the effectiveness of CR programme in reducing mortality, morbidity, promoting health and the quality life of patients with CVD, as well as preventing subsequent cardiac events (Jolliffe et al., 2001, Taylor et al., 2004, Lawler et al., 2011, Anderson and Taylor, 2014, Taylor et al., 2014, Heran et al., 2011). Furthermore, CR programmes tailored for women significantly increased the quality of life of those female patients, when compared with traditional CR models (Beckie and Beckstead, 2010). Jolliffe et al. (2001) analysed 32 randomised controlled trials (RCTs) reporting data from 8440 patients to compare the effectiveness of exercise-only versus comprehensive CR programmes. The results were somewhat surprising, as they suggested that the exercise-only programme showed a higher reduction in all-cause mortality (27%) and total cardiac mortality (31%) when compared with the comprehensive programme (26%) (Jolliffe et al., 2001). However, in the comprehensive CR groups, there was a more significant net decrease in lipid profiles (total cholesterol and LDL). Although, this review collected data from studies that involved predominantly middle-aged, low-risk male patients, these findings indicate that there is barely any difference in the outcomes of exercise-only programmes versus comprehensive programmes. A small-scale quasi-experimental study in South Korea by Kim et al. (2014) examined the effect of the delivery of a comprehensive CR programme. They recruited both male and female patients into the study, in which 33 participants were enrolled in the intervention group,

while 29 participants were in the control group. The results found that participants in the intervention group demonstrated improved physiological indicators: i) reduced BMI, ii) reduced waist circumference, and iii) increased LV diastolic function, as well as significant improvements in the quality of their lives. However, the researchers also reported that there was no difference between the intervention and control groups in terms of recurring symptoms or cardiac events. This study, however, suffers from low sample size and lack of randomisation.

Three research teams performed a meta-analysis to assess the effectiveness of exercise-based CR and reported consistent findings (Lawler et al. (2011); Taylor et al., 2014; Anderson et al., 2016). A small scope meta-analysis by Lawler et al. (2011) looked at 34 randomised control trials to estimate the effect of exercise-based CR on the CVD outcomes. The findings demonstrated that patients randomised to the programme showed a significant reduction in the risk of reinfarction, the risk of cardiac mortality, cardiovascular mortality, and all-cause mortality. Similarly, Taylor et al. (2014) analysed 33 trials involving a total of 4740 people to examine the effects of exercise-based CR for patients with heart failure. They found that compared with standard care, CR demonstrated a significant reduction of all causes of mortality and hospital readmission, in more than a 12 months' follow up, as well as lowering the cost of healthcare. In addition, CR also has proven to be effective to improve the health-related quality of life (HRQoL). After two years, Anderson et al. (2016) updated their previous review which included more trials than before. In total 63 trials, with a total of 14,486 people with CHD (<15% women), were included in the analysis. The findings were consistent with previous studies (Taylor et al., 2014, Lawler et al., 2011), in which exercise-based CR was effective in reducing the risk of cardiovascular mortality, thereby reducing the risk of rehospitalisation, and improving patients' quality of life.

While there is strong evidence supporting the effectiveness of exercise-based CR programmes, psychological and education-based interventions alone demonstrated little effect in reducing either mortality or hospitalisation (Anderson and Taylor, 2014). The latest update of the Cochrane review, which evaluated the impact of the psychological interventions as part of CR from documented CHD, was undertaken by Richards et al. (2017). A total of 35 studies, involving 10,703 patients, was included in this review. Results showed that there was no difference in terms of total mortality

and the risk of revascularisation between the patients enrolled in the CR with psychological intervention and those in standard care. However, patients who received psychological therapies showed some degree of reduction in their levels of depression, anxiety and/or stress.

The studies of the effectiveness of CR outlined above have demonstrated that men and women obtained similar benefits from their CR experiences. Beckie et al. (2011) conducted a randomised controlled trial to assess the impact of a tailored-CR on the levels of depression evident among women in the USA. A total of 225 women participated in this study, divided into two groups. The women enrolled in the tailored intervention exercised in the women-only programme, received a multiple behavioural change intervention and motivational interviewing. The results found that the women in the tailored group programme showed a greater reduction in depressive symptoms than women in the traditional CR group. The summary of CR benefits for women, presented in Table 2.1., is provided by Bennett et al. (2017).

Table 2.1 Benefits of CR in women

Physical	Psychological
Decreased	
<ul style="list-style-type: none"> • Hospitalisation • Mortality • Morbidity • Frailty 	<ul style="list-style-type: none"> • Anxiety • Depression symptoms • Stress
Improved	
<ul style="list-style-type: none"> • Microvascular disease • Angina symptoms 	<ul style="list-style-type: none"> • Patient-physician relationship • Quality of life
Increased	
<ul style="list-style-type: none"> • Control of menopause symptoms • Peak VO₂ • Functional capacity • Strength • Balance 	<ul style="list-style-type: none"> • Personal medical advocacy • Medication adherence • Heart-healthy behaviours • Social support

Source: Bennet et al. (2017, p. 4)

Overall, it is reasonable to assert that there is sufficient evidence to support the claim that CR benefits both male and female patients who suffer from heart disease. Despite the benefits, CR utilisation by women remains lower than for men (Brown et al., 2009, Neubeck et al., 2012). As such, further exploration of women's experiences of living with heart disease and their participation in CR are warranted.

2.4 Heart disease in women

According to Lockyer and Burry (2002), the traditional belief that CVD is a man's disease has caused CVD not to be considered as a serious health problem for women of all ages. LaCharity et al. (1997) noted women themselves thought that they are safe from heart disease until after menopause. For this reason, any association between women and CVD has been neglected by both feminists and healthcare professionals for many years. Women were less likely to be referred for diagnostic tests, to be less intensively treated, and more likely to be referred at a later stage in their illness (Bowling et al., 2001, Daly et al., 2005). However, during the last decade, it has been noticed that CVD concerning women has increased in research, clinical practice, and among the general public. The AHA launched a national campaign "Go Red for Women" in 2003 to raise the awareness and to increase the knowledge of the public about the hazards of CVD in women. This national campaign has spread to several countries and become a global phenomenon. Mosca et al. (2013) reported that these campaigns have successfully increased the awareness of the heart disease as the primary cause of mortality in women. However, educational efforts must still be made to reach the racial and ethnic minorities who have lower rates of awareness and higher CVD mortality and risk factors.

For the past three decades, there has been a dramatic decline in the mortality rate caused by CVD for both men and women, particularly in the >65 years age groups (Garcia et al., 2016). However, the report for developed countries such as the US, the UK, and Australia showed that heart disease remains to be the leading cause of death of women >65 years, followed by cancer and stroke (WHO, 2014a). In Indonesia, ischaemic heart disease (IHD) and stroke have been identified as the leading causes of premature deaths among men and women for the last decade (Mboi et al., 2018). The data from the Global Burden of Disease Study (2016) has noted a 14.2% increase in deaths due to IHD in Indonesia from 2005 to 2016 (Mboi et al., 2018). Based on the report from PERKI (2015), the proportion of women referred to the National Cardiovascular Centre in Indonesia, due to acute coronary syndrome, was as high as 22.4% of the total patients. Women's mortality rates in the nation's hospitals were 70% higher when compared with men (10.6% vs 6%).

The literature highlights the fact that women experience the initial presenting symptoms of heart disease differently to men. As reported in the Heart Disease and Stroke Statistics for 2012, almost two-thirds (64%) of women die suddenly of CVD, without exhibiting any previous symptoms (Roger et al., 2012). Central chest pain is not always the first symptoms of MI experienced by women (Beery, 1995). On the contrary, a more recent study (Thygesen et al., 2012) reported that the most common symptoms of MI for both men and women was central chest pain. Generally, ischemic symptoms in for both women and men can include: a) unusual fatigue, b) shortness of breath, c) any chest pain or discomfort, d) upper back pain, e) upper body discomfort, f) indigestion, g) heartburn, h) nausea/vomiting, i) palpitations, or j) tingling in the hands or arms (Roger et al., 2012, Centers for Disease Control and Prevention, 2013). However, Berg et al. (2009) reported that women usually display a greater number of symptoms than men.

The atypical symptoms of a cardiac event in women present challenges in diagnosis, so that women are more prone to misdiagnosis than are men (Ryan et al., 2005). In regard to diagnosis, the literature shows that women were more likely than men to experience delays in diagnosis and treatment (Agency of Healthcare Research and Quality (AHRQ), 2003, Maas and Appelman, 2010, Roger et al., 2012). In general, women suffer from CVD approximately ten years later than men (Anand et al., 2008). At this point, women have a higher risk of suffering from multiple comorbidities, such as diabetes or hypertension, which put women at high risk of CVD (Sharp, 1994, Jensen and King, 1997, Worrall-Carter et al., 2011). Therefore, when women do suffer from CVD, they have a higher probability of experiencing poor outcomes, including death (Pepine, 2004, Audelin et al., 2008, Reeves et al., 2008). A systematic review investigating the CVD risk for women found that physical inactivity, depression, and stress are associated with increased risks of women experiencing CVD (Worrall-Carter et al., 2011).

Eysmann and Douglas (1993) stated that there are sex or gender disparities in access to diagnostic and therapeutic modalities for coronary heart disease between men and women. Two decades ago, according to Eysmann and Douglas (1993), women were referred for coronary revascularisation later in the course of their disease. This time lag, if still evident, may be a contributing factor to the increase of in-hospital mortality rates after coronary angioplasty and CABG. Lundberg and King (2012) suggested that both men and women should receive equal treatment and evaluation since

women could gain similar benefits to men from invasive strategies. Recently, there have been many improvements in the diagnosis of women experiencing heart attacks; increments which have had significant positive implications leading to better patients' outcomes, as they have been provided with timely treatment (Dalal et al., 2015).

In making a clinical decision related to the diagnostic procedures and treatment of cardiovascular diseases, physicians tend to see CHD as a "man's disease", so they refer to the male experience of CVD as the standard (AACVPR, 2013). Historically, women who received PCI or CABG procedures experience higher mortality rates than do men (Weintraub et al., 1994, Kim et al., 2007). Their higher mortality rate might be due to women's comorbidities, such as: i) hypertension, ii) diabetes mellitus, and iii) left ventricular dysfunction (Lundberg and King, 2012). The higher mortality rate might also be because, in most cases, women suffer from CHD and receive treatment at a later age compared to men (Lundberg and King, 2012). Nevertheless, recent studies have shown that mortality rates for both men and women who received CABG are similar, after correcting for age and comorbidities (Lundberg and King, 2012, Duvernoy et al., 2010).

2.5 Women and cardiac rehabilitation

Gender discrepancies were not only evident in the acute care settings, but also in the rehabilitation phase of cardiac care. The clinical practice guidelines have clearly stated that women should participate in a CR programme following a cardiac event, such as Acute Coronary Syndrome (ACS) or revascularisation intervention (CABG or PCI). Despite many efforts to improve the rates of participation in CR programmes, in both developed and developing countries, the proportion of female patients attending CR programmes is much lower than men.

There are several factors identified in the literature as the underlying cause of women's lower than optimal participation in CR. The first issue is related to CR referral. O'Farrell et al. (2000) stated a 'gender bias' exists when it comes to referral to CR programmes. Many studies have identified the referral gap between men and women to CR programmes; a bias that heavily favours, and therefore benefits, men. Colella et al. (2015) analysed 19 studies reporting data of 241,613 participants (80,505 women) from the USA, Canada, Europe, Australia, and New Zealand. The findings suggested that from 2005 onwards, the referral rates to phase two CR

programmes have remained sub-optimal, particularly among women. The rates ranged from 22.2% at the low end to a maximum of 73.7%. In the pooled analysis, women (39.6%) were less likely to be referred to phase two CR than men. This result contradicts the existing clinical practice guidelines that suggest outpatient CR as the class 1 intervention for both men and women (Mosca et al., 2011, AACVPR, 2013). Otherwise, it confirms that gender bias in the referral of CR remains a significant challenge to be dealt with (Colella et al., 2015).

It is not only that referral rates remain sub-optimal that constitutes a problematic issue, but women are also less likely than men to enrol for a CR programme. Research suggests that underutilisation of CR among women has been documented for well over a decade and it is a global phenomenon (Scott et al., 2002). In 2015, the National Audit of Cardiac Rehabilitation (NACR) revealed the women's participation in CR in the UK remains lower than men (NACR, 2015). In 2017, there was an increase in the number of women attending CR; however, a large proportion of eligible female patients are still failing to attend CR (NACR, 2017). Many other studies also clearly indicate women's lesser participation in CR programmes (Beswick et al., 2005, Rees et al., 2005, Suaya et al., 2007). In a meta-analysis to examine sex-differences in CR enrolment, Samayoa et al. (2014) looked at 26 observational studies reporting data for 297,719 participants, of which 43.2% were women. In the pooled analysis, the enrolment rates for CR among women were significantly lower than men. A recent systematic review by Ruano-Ravina et al. (2016) also reported that women were less likely than men to attend a CR programme. However, the findings of the latest study in the UK by Galdas et al. (2018) which analysed data from 95,638 patients across England, suggest that there was no important gender differences between men and women that led to their initial engagement with a CR programme. They reported that the attendance rates of both men (66.5%) and women (62.4%) at CR remain sub-optimal. Galdas's study, therefore stresses that the factors that influence CR uptake are multifactorial, indicating that gender alone is not the primary determinant for CR attendance.

Once women do enrol in a CR programme, they are less likely to adhere to the programme than men. Moreover, many studies also reported a higher rate of dropout among women than men (Grace et al., 2002, Daly et al., 2002). Oosenbrug et al. (2016) performed the first meta-analysis to describe men and women's adherence to CR as well as to determine whether significant sex-difference persists. Fourteen

studies, with a total of 8176 participants, were included in the review. The results revealed that CR adherence among women is lower than men, with women averaging 5% fewer CR sessions than men (69% versus 64%). This sex-difference was particularly evident a) where programmes were delivered over a longer duration (>12 weeks), b) in studies conducted in Canada, c) in studies published after 2010, and d) in higher-quality studies.

The evidence indicates that sex-difference issues in CR exist in this era. Hence, here lies the paradox: the data shows that there has been an upward trend of mortality among women following a cardiac event, yet women were less likely to be referred to, enrolled in, or adhere to their CR programme, despite the proven benefits of CR for women (Sedlak and Humphries, 2016). For this reason, the issue of uptake becomes critical as this disparity predominantly affects the patients that would benefit most from a comprehensive programme. Examples of such patients are: i) females, ii) older aged, iii) from ethnic-minority groups, as these categories have more co-morbidities or are living in lower standard, socioeconomic situations (Beswick et al., 2004). The groups who were the least likely to be referred to CR are the same groups that experience the greatest morbidity and mortality following cardiac events (Grace et al., 2004).

It can be seen that the issue of women's less-than-optimal participation in CR occurred at different stages of CR, starting from referral, enrolment, up to the point of adherence to the programme. CR nurses have the potential to improve women's participation in CR programmes. Previous research has shown that a nurse-delivered bedside referral process increased women's participation in CR by 32.6% (Tiller et al., 2013). In the following section, I will explore the barriers and facilitators of women's referral, enrolment, and ongoing participation in CR programmes, as well as addressing the issue of women's motivation in their CR participation.

2.5.1 Factors influencing women's participation in CR

A vast number of qualitative studies have been carried out over the last decade to explore women's experiences in CR programmes. However, from the literature search, none of the studies was conducted within Indonesia, or even Asia. The majority of the studies that explored women's experiences of CR were carried out in

Western countries. Indeed, some studies investigated ethnic-minorities groups (South Asians in the UK or Canada) and/or migrant, but none of the studies explored the actual experiences of patients within an Asian geographical context.

The literature suggests that factors that influence CR participation are several and complex. However, there are three prominent themes identified from the literature: i) patient-level factors, ii) practical factors, and iii) health system/provider factors.

Patient-level factors

With regard to patient-level factors, previous studies have revealed many factors that contribute to women's low participation in CR programme (Jackson et al., 2005, Scott et al., 2002, Grace et al., 2009, Chauhan et al., 2010, Jones et al., 2007, Rose et al., 2011). Perceived and anticipated physical and psychological benefits of the programme were also reported as a significant factor that influences women's decision to attend a CR programme (Rouleau et al., 2018). Women tend to evaluate what they might gain from the programme; generally, women continued their attendance if previously they had positive experiences of exercise and its benefits, or their current programme was offering the same (Clark et al., 2013).

It is clear that misconceptions about the nature of heart disease, its underlying causes, and the importance of exercise for recovery, have also prevented women from attending CR programmes. Visram et al. (2008) found that cultural misconception was a central issue that hindered women's participation in CR programmes. The women participants in their study expressed concerns that physical exercise would be harmful to their hearts. Cooper et al. (2005) study found that a lack of knowledge regarding the underlying cause and risk factors relating to their heart attack made the participants believe that CR and lifestyle change were unnecessary. Similarly, in the study by Schou et al. (2008) the CR non-attenders expressed the opinion that heart disease is a non-life threatening condition; thus, they suggested that there was no need to attend a CR programme. Resurreccion et al. (2018) reported that one of the reasons for the women in their study to drop out of attending their CR programme was because they held the belief that heart disease was not a severe condition. In addition, negative experiences of programmes or programme providers, as well as the negative view of their heart disease, hindered women's participation in CR (Clark et al., 2013, Chauhan et al., 2010).

Chauhan et al. (2010) and Visram et al. (2008) identified that language barriers and communication difficulties with medical staff as significant barriers to CR participation among South Asian women, with CVD, in the UK. In addition, the research findings also raised sensitive issues related to religion and gender. The women participants described their reluctance to exercise in the mixed-gender classes due to their religion and personal values. Traditionally, for South East Asian women physical exercise was considered a masculine activity; thus, mixed-gender CR classes will almost certainly constitute a barrier preventing those particular female patients from attending. Besides, the clothing requirements for exercise are also considered incompatible with the women's traditional dress; particularly long headscarves. The women also felt uncomfortable with some of the material covered in the health education session, such as sexual relations, in a mixed-gender setting. However, there is a paucity of research on women's experiences of CR in Indonesia, which is a Muslim majority country; particularly in relation to their religious beliefs and being required to take part in mixed-gender physical activities. Further exploration is needed to understand the multiplicity of contextual factors that influence women's experiences in Indonesia, in order to provide the insights into the cultural differences which shape and inform women's experiences with cardiac rehabilitation programmes in Indonesia.

Practical factors

Distance and transportation issues were the most consistently cited by many women as the main practical barrier to access their CR programme (Cooper et al., 2005, Jones et al., 2007, Chauhan et al., 2010, Resurreccion et al., 2018). Cooper et al. (2005) reported that the women found it difficult to attend CR; a problem particularly related to the enormous cost if they had to use a taxi. The use of public transport was also cited as impractical by the women since they had to change buses a couple of times in order to reach their clinic (Jones et al., 2007, Chauhan et al., 2010).

Family obligations and roles also influenced women's CR participation. One woman in the study by Jones et al. (2010) stated she could not attend the CR programme because she was the primary carer of her sick husband. Resurreccion et al. (2018) interviewed ten women in Spain to identify their reasons for dropping out of their CR programmes. This study also identified work/family related obligations as the barrier to women's participation in CR. In a large qualitative systematic review by Clark et al. (2013) which assessed 62 studies involving 1646 patients (57% female) the authors

noted that both individual and contextual factors had influenced women's participation in their CR programmes. Clark and colleagues reported that women's occupational demands, as well as other social roles associated with childcare, family obligations, or housework often constrained women's participation in a CR programme. In addition to these inhibiting factors, a) distance from the programme, b) transportation issues, and c) lack of support from the family members, have also been identified as barriers preventing women from accessing CR programmes. These findings are corroborated by a systematic review from Neubeck et al. (2012) that identified two main types of obstacles. These obstacles were a) physical barriers, such as lack of transport, or work commitment and b) personal barriers, such as embarrassment, lack of knowledge about the CHD and the purpose of CHD; they were acknowledged as the key reasons for non-attendance in CR programmes for both men and women.

As discussed in section 2.6.1 (below), the concept of womanhood in Indonesia revolves around a woman's primary roles as a mother and a wife. Despite the freedom to pursue higher education or career, women are still frequently reminded of the natural, traditional roles associated with being the caregiver in the family. Therefore, it would be important to extend the investigation in order to discover how women's roles influence women's decision to participate or not to take part in a phase two CR programme in Indonesia.

Health system/provider factors

With regard to health system-provider-level factors, lack of referral or endorsement from the physicians, time-consuming enrolment processes, lack of an available CR programme, long waiting lists, and communication difficulties between staff and patients, are identified as the most common barriers to participate in a CR programme in the literature (Tod et al., 2002, Grace et al., 2004, Chauhan et al., 2010, Neubeck et al., 2012, Resurreccion et al., 2016). Many studies have identified a recommendation and referral from a healthcare provider as the most influential factor affecting participation in a CR programme (Grace et al., 2002, Jackson et al., 2005, Banerjee et al., 2010). Jackson et al. (2005) found that a physician's recommendation is not only a catalyst for enrolment in CR, but also the most reliable predictor for CR adherence. As part of a more extensive study exploring the Women's Cardiovascular Health Initiative (WCHI) in Canada, Rolfe et al. (2010) interviewed 14 women who enrolled in the WCHI. The analysis revealed that many participants cited a physician's

strong recommendation as the most influential reason for their enrolment in the CR. However, not all participants received a recommendation from the physician; thus, they had to negotiate strategies to acquire a referral to the programme.

Many studies have identified strategies to improve women's participation in CR. These strategies include automated referral systems, liaison contact, and early enrolment after hospital discharge, to try to address and overcome the common CR barriers for women. Furthermore, incentive programmes, flexible hours, as well as the use of alternative delivery CR models are identified as the strategies to reduce the rates of 'dropping out' from CR (Supervía et al., 2017, Rolfe et al., 2010). According to Grace et al. (2011), the implementation of a combination of systematic and liaison referral strategies is effective for improving CR enrolment rates among women. Based on the knowledge gained from this study, improving the rates of, and access to a physician's endorsement and recommendation is essential in order to facilitate women's participation in CR. Despite the many attempts to improve women's attendance rates in CR programmes, the literature suggests that the number of women participating in CR remains lower than men.

Motivation to attend CR

In terms of motivation to attend CR, there is a slightly different motivation between men and women. Previous studies have revealed that women valued the social and emotional support of CR, while men focused on practical health and wellbeing related support and advice (Hagan et al., 2007, Schou et al., 2008, Chauhan et al., 2010, Sutton et al., 2012, Clark et al., 2013, Angus et al., 2015, Dechaine and Merighi, 2017). A qualitative study by Dechaine and Merighi (2017) explored men's and women's challenges and motivations related to CR. They interviewed 20 women and 20 men in Minnesota, USA. Their findings revealed both men and women shared similar intrinsic motivators for their attendance, which were basically to improve their physical and emotional health. However, women's motivation differed from the men, in that the women focused more on seeking emotional support and building relationships with staff and other participants participated in CR. In contrast, men paid less attention to developing relationships and more on framing their CR participation as a task that can be mastered. Sutton et al. (2012) conducted a study to examine the role of safety for women's engagement in the CR programme in Canada. They collected the data through a semi-structured interview with 14 women aged between

28-83 years. The findings suggested that safety factors were a necessary consideration for the women in their decision-making about whether: a) to participate in a CR programme and b) to continue their exercise regimen or not. Despite there being an extensive literature reporting on this subject, there is a paucity of research in Indonesia that has examined this topic. Several previous studies on patients with cardiovascular disease or cardiac rehabilitation were directed to investigate the biomedical aspects of the disease, as well as the effect of a specific intervention for patients (Radi et al., 2017, Ragawanti, 2014, Abdurachim et al., 2007, Badriyah, 2014). Despite these investigations, the factors that led to women's attendance at CR were still under-explored. Hence, it is important to understand the fundamental issues that influence participation in CR programmes so that an appropriate 'culturally-sensitive' and 'gender-sensitive' programme could be developed in Indonesia and then implemented.

2.5.2 Gender and cardiac rehabilitation

Sex has been defined as a classification, generally as male and female, according to the anatomical and physiological differences (Punch et al., 2013). On the other hand, gender can be defined as "*socially constructed roles, behaviours, expressions, and identities*" of men and women (Institute of Gender and Health, 2018).

Doull et al. (2010) conducted a systematic review appraisal to investigate the use of sex- and gender-based analysis (SGBA) in systematic reviews of CVDs. The findings showed that among 38 reviews included in the study, sex and gender were rarely considered in the Cochrane systematic reviews of CVD interventions. Nowatzki and Grant (2011) suggest that research based on sex-disaggregated data alone would be less useful if it does not include gender-based analysis. Sex is not the same as gender. Nowatzki and Grant (2011), therefore, defined sex as 'a poor proxy of gender' due to its inability to capture the full range of social, political, and economic forces that affect health. Administrative data alone are insufficient for identifying the extent to which health services are responding to the specific needs of women and men, or how strategies may be formulated to address unmet needs (Scofield, 2004).

Using a gender-sensitive approach, Emslie (2005) analysed 66 qualitative studies to explore patients' experiences of CVD. The results highlighted the under-representation of women in qualitative studies during the 1970s and 1980s. This

under-representation began to change in the 1990s when several studies started to recruit women as participants; by the end of the 1990s more studies were being conducted with exclusively female participants. Despite the inclusion of men and women in most studies, the majority of the research was not informed by a specific gender theory. Thus, Emslie suggested that more research should adopt a gender-sensitive approach to increase the effectiveness and efficiency of services designed to implement CVD interventions. Melloni et al. (2010) also noted the under-representation of women in clinical trials of CVD prevention. Although enrolment of women in RCTs has increased over time, their inclusions in clinical trials remains low relative to their representation in affected population. The mean percentage of women enrolled in such trials for CVD prevention is only 30%, while only one-third of the trials specifically reported results for women. Therefore, in making a clinical decision related to the diagnostic procedures and treatment of cardiovascular diseases, physicians tend to refer to the male experience with CVD as the standard (AACVPR, 2013).

There is a predominant conception about health-seeking behaviour among men and women, which assumes men are more reluctant than women to seek help, irrespective of the nature of their concern (Courtenay, 2000, Möller-Leimkühler, 2002). The concept of masculinity may well prevent men from seeking healthcare, as it is often perceived by them as a feminine practice (Courtenay, 2000). On the other hand, women are generally seen as having poorer health and are more likely to obtain formal healthcare than men; behaviour which may be associated with female characteristics (Ladwig et al., 2000, Lahelma et al., 1999). However, there are some critical voices claiming that this assumption is oversimplified. Macintyre et al. (1996) argue that the significant determinants of men and women's health-seeking behaviour will depend on the clinical manifestation of the disease, as well as the age of the patient.

There are abundant numbers of qualitative studies that explore the barriers and facilitators to CR; however, those studies have not been well explored for gender-related themes (Angus et al., 2015). According to Angus et al. (2015), the poor attendance of women at CR programme should be studied as a matter of 'gendered access disparity' in order to understand the underlying mechanisms of women's CR participation. Gender is highly relevant as a lens through which to study social processes that underlie access and disparities in health service use.

2.5.3 Summary

I have presented some basic concepts associated with cardiac rehabilitation, including its definition, components and organisation; as well as the benefits of CR for both men and women. CR is a multidisciplinary and multifaceted intervention which has been proven to be effective in reducing the mortality and morbidity rates of patients with CVD, as well enhancing the quality of life of those patients. For this reason, international and national clinical practice guidelines highly recommend CR for patients with a wide range of cardiac conditions, including acute coronary syndrome, heart failure, or revascularisation interventions (CABG, PCI). Despite many efforts to improve the rates of participation in CR programmes, the literature suggests that CR is still grossly underutilised, particularly among women. Many studies have been conducted to identify and confirm the underutilisation of CR programmes among women. It is reported that the factors that lead to women's lesser participation at CR are multifactorial, including patient-level, health system-level, provider-level, and programme-level factors. Despite the abundant number of research studies that have explored the barriers and facilitators informing the uptake of CR, there remains a dearth of research investigating the CR experiences of patients with heart disease in Indonesia. Previous studies around CR programmes in Indonesia were more focused on the biomedical impact on the patients of such intervention programmes (Ragawanti, 2014, Radi et al., 2017), rather than exploring the patients' actual experiences of, and perceptions regarding, the programme. For these reasons, it is important to conduct research to explore the Indonesian women's experiences of living with heart disease, as well as their experiences in attending CR programmes. This research initiative is necessary in order to identify the components required to create a relevant and more acceptable-to-women CR programme in the future.

2.6 Theoretical Perspectives

During the process of developing this research, I considered various theoretical perspectives. According to Crotty (1998), theoretical perspective is the philosophical position informing the methodology. Moreover, Crotty (1998) argues that the ways of researching the world are strictly related to the ways of viewing it. For this reason, it is essential that the researcher has knowledge of the theoretical perspective informing

their research. In this thesis, feminism is used as a philosophical lens through which to understand women's experiences living with heart disease and also their attendance or non-attendance of their CR programmes. Therefore, in this section of the literature review, I will discuss feminism in Indonesia as the main frame of analysis and Western feminism, as well as more specifically the concept of intersectionality.

2.6.1 Feminism in Indonesia

The development of feminist theories in Indonesia differs from the phenomenon in Western countries, in a way that Indonesian scholars have developed feminist discourse through various forums located outside of university contexts (Arivia and Subono, 2017). In addition, international meetings have also influenced the development of Indonesian feminist perspectives that sharpened analytical sensitivity among Indonesian feminist scholars. Limited access to books and journals, together with a university system that acted as an extension of the state's interests in the 1980s and 1990s, encouraged the scholars to become autodidacts, outside the university curriculum. In contrast, Western feminist scholars have a role in universities to produce critical discourse to be used by grass-root movements (Stanley and Wise, 1993).

The social construction of womanhood in Indonesia has been strongly influenced by the blend of state ideology, Javanese cultural traditions, and Islamic norms (Ida, 2001). Almost 90% of Indonesia's total population is Muslim, which makes it the largest Muslim majority country in the world. Islam had been in Indonesia since the eighth century but does not appear to have begun to take hold until the beginning of the 13th century. Islam maintains a distinctive identity, particularly with its emphasis to *fiqh* (Islamic jurisprudence), which includes the knowledge, the understanding of the guidance, the rulings, and the interpretation of Islamic jurists over many centuries (Rinaldo, 2011).

It can be said that the discussion around feminism including feminist theories, figures, and histories in Indonesia, still presents a considerable challenge. Although it should be acknowledged that since the beginning of the reform era in 1998, there has been more freedom and openness in the discussion of women's rights issues (Arivia and Subono, 2017), other problematic issues remain. Up until now, there has been an ongoing controversy on the use of terms such as 'feminism', 'feminist', and even

'gender' among the majority of Indonesian society. Many people viewed feminism as a non-native, Western ideology, and as such is considered to be irrelevant to Indonesian values (Sadli, 2002). Despite the fact that the principle of gender equality is embodied in article 27 of the 1945 Constitution, many negative assumptions regarding feminism remain; for example: feminists are anti-men, promote lesbianism and so forth. For these reasons, many women activists in Indonesia are reluctant to be called a feminist, although there is no doubt their work represents the idea of feminism (Arivia and Subono, 2017). Therefore, despite the unwillingness of the Indonesian activists to use the term feminism, the focus of their struggles or areas of research was actually consistent with the spirit of feminism. In short, the development of feminism in Indonesia comprises four phases (Arivia and Subono, 2017).

- 1) The first phase was the colonial phase or feminist liberal phase.
- 2) The second phase was the Social-Marxist phase under Soekarno regime.
- 3) The third phase was feminism during the New Order regime (from the late 1960s to 1998).
- 4) The fourth phase is the contemporary phase that has grown to be very visible since the end of the New Order era in 1998.

The women's movements during the colonial phase were not well documented in the Indonesian historical literature. In 1920, the idea of women's rights stemmed from women's activities in the nationalist organisations, which had women's wings (Arivia and Subono, 2017, Rinaldo, 2011). Through such channels women entered the public arena and even participated in the Youth Congress Pledge (*Sumpah Pemuda*), which was declared in 1928. During the 1920s and 1930s, not only were women involved in the nationalist women's organisations, such as *Putri Mardika* (Free women), *Madjoe Kamoelian* (Progress and honour), *Isteri Sedar* (Women Aware), but also in Muslim-based organisations such as Aisyiyah, which was the women's wing of Muhammadiyah. These women's organisations were concerned with equal rights for women in marriage, improving women's working conditions, equal wages, prostitution, and trafficking. However, it should be noted that the secular and Muslim women's organisations were often divided, particularly when discussing issues such as polygamy (Robinson, 2009).

History has recorded several remarkable women who took part in the struggle against colonialism, such as Cut Nyak Dien and Cut Meutia from Aceh, or Martha Christina Tiahua from South Sulawesi. Apart from the armed struggles with their male counterparts to fight against Dutch, the women's movements during this period were focused on promoting women's suffrage - not only the right to vote but also to be voted for - as well as to fight for access to education. The first female journalist, Rohana Kudus who managed *Soenting Melayu* (Malay ornament) in 1912, was one of the pioneering vocal figures and often raised sensitive issues in the newspaper; such as polygamy, access to education for females and skills for women. However, the most prominent figure was Kartini (1879-1904). She was born into an aristocrat family; her father served as Governor under Dutch colonial administration. Thus, unlike many other Indonesians, she had the opportunity to attend a Dutch school. However, at the age of 12, she was forced to withdraw from school because she was a woman. Following that, she spent the next decade in correspondence with her Dutch friends. Her letters were published in a book "*Door Duisternis Tot Licht*" (1911), and later the book inspired many Indonesian women after it was translated from Dutch into Indonesian: "*Habis Gelap Terbitlah Terang*" (Out of Dark Comes Light). The book became a source of inspiration for Indonesian women to fight for their self-esteem and dignity to be equal to men (women's emancipation) through education. In brief, Kartini proposed the basic ideas of women's right to education and equal opportunity with men to work and have a career (Wieringa, 1988).

GERWANI (Indonesian Women's Movement) was one of the most prominent women's organisations in the 1950s before it was terminated, in effect destroyed, in 1965. GERWANI played a prominent role socially and politically in the two earliest eras of democracy in Indonesia (from the end of the 1940s to 1965) known as liberal democracy and then guided democracy, the latter during the authoritarian leadership of Soekarno (Arivia and Subono, 2017). By 1954, the members of GERWANI reached 80,000 women, and continuously expanded its members to recruit women from grass roots level. Although GERWANI members rarely labelled themselves as feminists, their movement was inspired by communist ideology, which incorporated idea of women's equality (Wieringa, 2002). However, in 1965, Indonesian politics experienced a drastic change following the tragedy that became known as 30 September movement. After the attempted coup in that year, the leftist women's organisation, GERWANI became one of the primary targets of destruction by armed forces under

General Soeharto. It was evident that the political and military orientation under the New Order regime strongly opposed organisations that tried to mobilise the communities at grass root level in Indonesia. At that point in our history basically all the notions of the rights of citizens came to an end (Arivia and Subono, 2017).

From 1965 to 1998, Indonesia was ruled by an authoritarian regime under the leadership of Soeharto. In the beginning of the New Order regime, many Muslim groups were supporting Soeharto, particularly due to his anti-communist sentiment. However, after 1970s the national ideology was aligned under Pancasila, the Indonesian state philosophy, that started to suppress political Islam and other opponents through coercion (Mutaqin, 2018). Blackburn highlights,

“Indonesia has a history of prioritising the communitarian tradition of citizenship: rights are perceived as belonging to communities rather than to individuals, often to the disadvantage of women who are expected to fulfil numerous obligations but to have few rights. Since independence, authoritarian regimes have built on some traditional notions of citizens’ responsibilities, reinterpreting them in forms suited to the modern state.” (Blackburn, 1999)

During the time of Soeharto’s New Order, the government started to use politics to control women’s affairs to support government policy in a strict way (Qibtiyah, 2009). The government implemented programmes that focused more on putting women back into the domestic sphere in a purely supporting role, instead of encouraging women to be leaders (Blackburn, 1999). Therefore, during this period, women were associated with their two primary roles as *‘istri’* (wife) or *‘ibu’* (mother), or both, as the most convenient gender ideology (Sunindyo, 1996). Under this ideology, women’s rights were strictly limited. As Blackburn (1999) stated,

“Women were supposed to accompany their husbands, educate their children, be supplementary income-earners, housekeepers, and members of the Indonesian society – in that order.”

The New Order regime promoted a culture known as *‘ikut suami’* (wife must follow husband). In this sense, women’s involvement in national development was merely as dependent assistants to the men (Sullivan, 1991). This formulation is crystallised by the state’s creation of the compulsory organisation for wives, *Dharma Wanita*, of which all civil servants’ wives were obliged to become members. The creation of

Dharma Wanita reflected the notion that women are defined in their capacity for serving their husband, their family, and the state (Suryakusuma, 1996). In addition, the government also disseminated gendered responsibilities through the creation of PKK (Family's Welfare Guidance). This organisation was created to support and implement the National Development policy, especially to ensure the success of the family planning programme to control the birth rate (Suryakusuma, 1996). Blackburn (1999) stated that since the 1970s, women's most important role in supporting the country's development was by becoming 'a responsible mother', which involved limiting the number of children. Contraception was considered, and in effect made, a woman's responsibility.

In other words, during the New Order era, women were defined as "citizens with gendered responsibilities" (Blackburn, 1999). Meanwhile, the notion of gender roles should comply with the amalgamation of '*priyayi*' (Javanese bourgeois class), in which people could contribute to both the material and moral betterment of themselves and the nation. Djajadiningrat-Nieuwenhuis (1987) noted:

"The role of ibu became more than that of a mother who feeds and looks after her children. But also the new Indonesian society called upon the 'kaum ibu' [community of Mothers] to put their shoulders to the task of building a new national state; ... The honour they could gain was that of being a good 'ibu'. Power and prestige remained the privilege of men."

Hence, the concept of the womanhood in Indonesia, as promoted during the New Order era, was what Suryakusuma (1996) referred as a 'state ibuism'; a concept which defines women as merely: i) a companion to her husband, ii) as a procreator of and for the nation, iii) mother and educator to their children, iv) a housekeeper, and v) a member of Indonesian society, in that order. Therefore, within the 'state ibuism', women were discouraged from participating in politics, and their appearances in public were limited to their 'state-required' roles as mothers and supporters of their husbands. The New Order government claimed those roles as a distinguishing concept of womanhood in Indonesia, which differs greatly from the Western conception (Sunindyo, 1996).

2.6.1.1 Women in contemporary Indonesia

The literature describes the overall intersection between patriarchy, culture, and religion in shaping women's identity in Indonesian society. However, what exactly has changed in relation to the women's roles and status in the country, since the beginning of the Reformation era in 1998, remains controversial. Undeniably, over the last two decades there has been a noticeable increase in the public presence of women and enhanced free speech for all (Hatley, 2008), although neither of these phenomena goes without being contested. The reform era has opened the gates for both progressive and conservative forces in many aspects of life in Indonesia. The emergence of the Islamic movement in the post New Order era is the primary source of most of the resistance to women's freedoms of expression in the media and society. Representatives of conservative Islamic groups condemn women's body exposure as undermining the moral order and traditional identity of Indonesian society. This leads to the implementation of culturally acceptable Muslim-centric measures such as rules of dress and behaviour for women, and the practice of polygamy in some regions.

After the fall of President Soeharto in 1998, an event which marked not only the end of the New Order regime but the beginning of the democratic reform era, the issue of women's rights returned to prominence in Indonesia. Contemporary feminist thoughts have been initiated since the beginning of the 1990s by a network of women's NGOs which actively and overtly used terms such as 'gender equality' and 'feminism', following the ratification of the UN "Convention on the Elimination of all Forms of Discrimination against Women" in 1984 (Rinaldo, 2011). These NGOs consisted of a group of young women who called themselves 'Indonesian feminists' (Sadli, 2002). They focused on assisting and advocating women to gain empowerment, to strengthen labour rights, as well as to fight against sexual harassment and gender violence. These movement show that despite the most repressive period of Indonesian politics that attempted to put women back into their *kodrat* (biological determination or nature), women were still able to find a space to develop their feminist thoughts (Sadli, 2002). However, until the mid-1990s, the women activists were primarily secular woman from elite backgrounds (Blackburn, 2004, Robinson and Bessell, 2002). There was a backlash against feminism, with critics accusing it as damaging religious (ie. Islamic) values. In the last decade, however, many Muslim women activists have started to participate in the discourses on gender equality.

The position of women in the post-reformation era in Indonesia is still considered problematic. The issue is a basic dichotomy: i) should they still follow the traditional identity of Indonesia that upholds the ideal norms of Javanese culture and the tenets of Islam, or ii) should they follow the global movement and embrace modernisation, informed by values from Western culture. In reality, although women have the freedom to pursue whatever they want in life, several studies about women and culture in Indonesia have concluded that women's status is still subordinate to men within the family and the state/government (Mulia, 2009). Although changes in policy and cultural customs have slightly shifted the perception of women in Indonesia, the cultural practices, customs, and beliefs continue to influence women's role in Indonesian society. For example, in a study on attitudes toward gender roles among university students in urban Indonesia, Utomo (2016) reported that amidst the higher-educated younger generation of Indonesia, neo-traditional notions of gender roles are still upheld. Although both genders supported the employment of married women, many of them still believed in the notion that males should be the breadwinner for the family. However, because this study was only carried out in two major cities in Indonesia, with highly educated research populations, the findings cannot be generalised to Indonesia as a whole.

The contemporary feminist movement in Indonesia proposed two main ideas prior to and at the start of the Reformation era. These include: firstly deconstructing sexist discourse and promoting feminist knowledge through academic activities and second, emphasising the discourses on pluralism, equality, and transnationalism (Arivia and Subono, 2017). This type of feminism is very distinct from feminism from the previous era. The feminist perspective in this era is used as a basis in the movement's fights to reject subordination and to improve women's lives (McCann and Kim, 2013). The latter issue involves a focus on such topics as gender violence, trafficking, polygamy, sexuality, human rights and 'woman as victim'.

2.6.2 Western Feminism

I was astonished at the number of different perspectives on feminism and meanings given to feminist concepts in the literature. This plethora reflects that feminism is not a fixed body of thought but a constant evolution of thoughts and actions related to various women's issues. Disch and Hawkesworth (2015) argue that any definition of feminism can be contested. Watkins (2000) suggests that feminism should not be

associated with a movement against the men, yet it is about the political struggles for women's empowerment. However, Watkins (2000) also noted that the lack of consensus on what feminism actually entailed has sometimes caused dilemma and confusion. As a social movement, feminism takes many forms, since many women have contributed to feminist theorising in many different situations and from many perspectives (Kolmar and Bartkowski, 2000). Nevertheless, what unites these different feminist strands is the overarching tenet that gender/sexual difference is a crucial determinant of social injustice. Annandale and Clark (1996) stated,

"Basic and common to all feminism is the understanding that patriarchy privileges men by taking the male body as the 'standard' and fashioning upon it a range valued of characteristics (such as good health, mastery, reason, and so on) and, through a comparison, viewing the female body as deficient, associated with illness, lack of control, and with intuitive rather than reasoned action." (Annandale and Clark, 1996, p. 19).

Based on this assumption, the fundamental issues that have concerned feminist theory are women's inequality and oppression by "patriarchy", understood as a system of women subordination based on economic relations (Kolmar and Bartkowski, 2000). In the 18th century, sexual dimorphism, "differences in male and female physiology/appearances" was used as a basis to differentiate social roles and responsibilities between men and women as well as to exclude women from any political participation. Sex that is typically conceptualised as an individual attribute; for feminist theorists, it is a political construct. Robert Stoller (1968) popularised the term 'gender identity' to describe the aspect of femininity and masculinity displayed by a person which was the product of a determined socialisation (Vigoya, 2015). Gendering is the product of particular ways of thinking that privileges men while disadvantaging women (Disch and Hawkesworth, 2015). Moreover, Disch and Hawkesworth (2015) assert that:

"Feminist theories arise in conjunction with feminist activism and academic practices, seeking to illuminate the barriers and constraints that circumscribe women's lives, explain their dynamic and persistence, and identify mechanism for change. From the outset, feminist theories have been diverse and contentious, reflecting the specific conditions of their emergence." (p.3)

In 1980s, feminist scholars made a specific complaint that research is owned by powerful (men) and that only certain questions can be asked, in certain ways within

male-centred frameworks of explanation (Holloway and Wheeler, 2010, Stanley and Wise, 1993). The domination of scientific methods by a patriarchal consciousness does not allow women to ask how women are politically situated in relation to men, since this method does not provide appropriate theory and concepts (Ramazanoglu and Holland, 2002b). For these reasons, many feminists have criticised social sciences as they often omit or distort the experiences of women (Stanley and Wise, 1993). Therefore, the fundamental principle of feminism is mainly concerned with the experiences of women in terms of their social, political, and economic inequalities.

Western feminism can be charted through a trajectory that starts from the concerns about sex and gender, nature and culture; through concerns with racial and sexual exclusion and emergent theories of power and gender in constituting the subject (Hemmings and Brain, 2003). In the late 19th and early 20th centuries, women's movements were focused on women's suffrage and women's equal rights (i.e. access to education, better working conditions) in the society (Smith-Taylor, 2015). Feminist scholars believed that education could be one way to liberate women from oppression and put them on an equal footing to men. From the 1960s, feminism emerged from the sexual emancipation of women and drew attention to a broader range of issues, including: i) legalising birth control, ii) equal opportunities in career, iii) sexism and patriarchy, iv) domestic abuse, v) marital rape, and vi) the sexual liberation of women. Two substantial works during this period were Betty Friedan's "The Feminine Mystique" and Simone de Beauvoir's "The Second Sex". Beauvoir (2010) defined the term 'sex' as the biological determination of male or female, whereas 'gender' was the social definition of feminine and masculine. Beauvoir (2010, p. 330) argued "one is not born, but rather becomes, woman," emphasising that people learn gender roles through the process of socialisation rather than an innate, or fixed-set of characteristics.

The assertion from Beauvoir that one is not born, but instead becomes a woman, refers to the process of gender socialisation or sex role theories, which emphasises the importance of environment in the construction of gender (Mikkola, 2017). In this sense, masculinity and femininity are socially constructed through a mechanism of social learning (Oakley, 1972). With regards to social learning theory, Bandura (1977) assert that children learn their appropriate gendered behaviour and characteristics through the process of imitation and modelling, such as by observing their parents,

and through reinforcement of specific 'appropriate' behaviour (Bandura, 1977). However, social learning theory has been criticised for oversimplifying gender differences (male-female binary), as well as ignoring children's own views and agency.

The third wave of feminism, also known as post-feminism or revisionary feminism, that started from 1990s onward, rejected the concept of gender realism: the idea that universalises women's experiences (Smith-Taylor, 2015). Feminists who dismissed this theory argued that if women shared some "golden nugget of womanness", all the women would experience womanhood in the same way, regardless of their social and cultural backgrounds (Spellman, 1988, p. 159 as cited in Mikkola, 2017). Third-wave feminism was not only focused on rejoicing individuality but simultaneously embracing inclusiveness and diversity (Smith-Taylor, 2015). The diversity of women was recognised, and emphasis was placed on identity, gender, race, nation, social order, and sexual preference. This multiplicity led to the inclusion of intersectionality in the feminist literature; a concept that may be defined as the acknowledgement that a variety of identities are simultaneously present in any individual, impacting the actions of that individual and the unique ways they perceive society (Crenshaw, 1989). Third-wave feminism accepted pluralism as a part of reality. The focus of third-wave feminism was more on micro-politics of gender to make feminism more accessible to new audiences as well as seeking increasingly equal opportunities between men and women in both the workplace and in the *home* (Smith-Taylor, 2015).

The many variations of feminist thoughts and ideas were consistent with the assertion from Harding (1987) who stated that the notion of one universal women's experience is impossible to exist since gender alone could not shape women's lives. There are multiple intersecting factors, such as ethnicity, class, race, age and education that influence how women interpret and value their individual existence (McCormick and Bunting, 2002). Therefore, postmodern feminists view empiricist and standpoint feminists as reverting to essentialist claims, viewing women as one single group that shared a single perspective that is different from men's (Leavy, 2014, Cosgrove, 2003). Feminists working from a social constructionist perspective are interested in examining the implicit assumptions embedded in traditional psychological research and theory.

“As in the case with other theoretical positions, researchers focusing in gender issues in health do not tend to explicitly align themselves with one particular theoretical paradigm in making sense of their data, but are rather inclined to invoke a position that might generally span a number of overlapping theoretical perspectives.” (McDonnell, 2009, p. 153)

Very early on the research process, it became clear to me that I would need to access feminist literature to inform, shape, and guide the research process. In this study, I believe that there is a gap in the knowledge regarding women's participation in CR programme; therefore, this study aims to elucidate bias and inequity in the way women were treated in the cardiovascular area by providing a thorough exploration on women's experiences. For this reason, I decided to inform my study with feminist literature and adopt a feminist perspective. The main assumption I brought into this study was in line with the underlying assumption of all the traditions of feminism, which is human equality. Hence, I object the discrimination of women made based on gender. I believe that all the women should have the choice of everything in their lives and they should have equal opportunities as men do in day to day activities. Concerning their participation in CR programme, I believe that despite their gender roles within the family and society, women should be given the same options to decide for themselves so that they would be able to make informed choices for their health. Specifically, feminist literature was accessed for the following reasons:

1. Feminist research aims to address gender inequalities. Given the gender inequalities that exist in cardiovascular health care (see section 2.4 and 2.5), a feminist perspective allowed for an exploration of these.
2. My study participant was made entirely of women. A feminist perspective 'gave-voice' to the participants.
3. The adoption of a feminist perspective assisted me in understanding the data that I had collected.

Ramazanoglu and Holland (2002a) claimed that what is essential when doing feminist research is to understand the experiences of women and give voice to those experiences. My study did focus on the experiences of women with cardiovascular disease in Indonesia. By conducting this research, I hope that their experiences would be heard so that it could be used to inform policy and practice to improve healthcare

services, particularly for women with cardiovascular disease. Based on these assumptions, I justify this study as feminist research.

Feminist theory was employed during my study's data collection, analysis and interpretation, discussion, and recommendation. During the planning and implementation stage, gender was given considerable attention. Data were also analysed to ensure that gender was considered. Further, the women in my study partially defined themselves with the social roles they performed; mother, wife, housekeeper/carer, for example, and so an exploration on how social roles can shape the self was also undertaken and this, again, was informed by feminist theory.

Feminist principles are more attentive to the topics of gender and health that highlight concerns and issues that may be inconspicuous within the traditional framework. Through recognising the significance of a) equality, b) inclusiveness, c) valuing the individual, context, power, and privilege, feminists have inspired the women's health movement in many ways (Travis and Compton, 2001). By paying close attention to the meaning and importance of women's personal experiences, it is possible to see that many health issues and inequalities are rooted in women's oppression.

2.6.3 Intersectionality

Many studies in health inequalities still focus on one main factor, such as socioeconomic position or social class as the primary cause of health differences among people in society. Kapilashrami et al. (2015) argue that health inequalities should be interpreted as a complex interplay between identity, social position, and other social determinants of health, using the concept of intersectionality.

The concept of intersectionality was first offered by Crenshaw (1989) as a critique to the mainstream (white) feminism movement that frequently ignored the experience of African-American women. She argued that the experiences of many black women were not addressed appropriately by white feminists; thus they called for a feminist practice that focused on their experiences. Intersectionality was defined as "*the multidimensionality of marginalised subject's lived experiences*" (Crenshaw, 1989, p. 139). According to Davis (2008, p. 68):

*“Intersectionality refers to the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in **terms of power.**”*

Within intersectional perspectives, multiple axes of social positions such as gender, social class, ethnicity, race, age and sexuality are mutually constituted to shape people's lives and health experiences (Collins, 2000). Under this assumption, individual accounts should be investigated, as located within simultaneous power relations of class, gender and ethnicity, without reifying social groupings. As Kapilashrami et al. (2015) stated, social dynamics rather than social categories should become the focus of the researchers. Despite its significance, there is still a lack of methodological guidelines in conducting research utilising an intersectional approach.

It has been mentioned several times above that there has been an access disparity between men and women joining, or being referred to, CR programmes. Hence, in this study gender inequalities become the focus of analysis. Gender inequalities represent the unequal positions of men and women in society; a situation which, in turn, leads to differences in their health and well-being as well as access to health resources (Kapilashrami et al., 2015). Therefore, in this study gender was identified as the point focus in the broader intersectional analysis. According to Kapilashrami et al. (2015), integrating gender perspectives within the intersectional framework can be achieved by acknowledging multiple dimensions of social position of the individuals, and then by identifying how gender is intersected with other areas of individual's social position. Shields (2008) points out two critical points stressing the significance of intersectionality when thinking about gender:

“First, it promised a solution, or at least a language for the glaring fact that it is impossible to talk about gender without considering other dimensions of social structure/social identity that play a formative role in gender's operation and meaning...Second, intersectionality seemed a generally applicable descriptive solution to the multiplying features that create and define social identities.” (p. 303)

2.7 Chapter Summary

The theoretical framework in this thesis is feminism which comprises the notions of: i) emancipation, ii) empowerment and iii) giving voice to women. By paying close attention to the meaning and importance of women's personal experiences, it is

possible to see that many health issues and inequalities are rooted in women's oppression. The feminist movement in Indonesia has been presented to give an overview of how women's roles evolved, following the change(s) in the political directions of the country.

CHAPTER 3: Research Design and Methods

3.1 Introduction

This chapter presents a comprehensive explanation of the research design and methods used to answer the research questions, as well as the philosophical assumptions underpinning this study. In section 3.2 I begin by outlining the research aim and research questions that were set and explored. Section 3.3 discusses the ontological and epistemological positions adopted in this study. In section 3.4 I discuss the rationale for adopting a feminist-informed qualitative research model. In section 3.5 the research methods undertaken in this study are discussed, together with the method of data analysis. Lastly, in 3.7 I conclude with a discussion relating to a) ethical considerations and b) the trustworthiness of this research and its findings.

3.2 Research aim and questions

In the previous chapter, evidence was offered to show that sex and gender differences are evident in the results obtained from participating in CR programmes. Therefore, the overall aim of this thesis is:

To gain an understanding of women's experience of heart disease and attendance in phase two cardiac rehabilitation programmes in Indonesia.

To achieve this aim, three research questions were derived from this major focus:

1. How does gender shape women's experiences of living with heart disease?
2. How do women decide to participate in phase two CR programmes?
3. What are the contextual factors that influence women's attendance in a phase two CR programme?

3.3 Philosophical Assumptions Underpinning the Study

In order to address the research questions, this study required an exploratory approach. I required an in-depth understanding of the social processes, relationships, and general contextual factors involved in the women's lived experience of heart disease, which in turn influenced their decision to attend and complete a phase II CR

programme. In this section, I analyse my ontological and epistemological approaches that underpinned the choices that informed the research process.

3.3.1 Ontological and epistemological perspective

This research study is supported by a relativist ontology and a social constructionist epistemology. Crotty (1998) has defined ontology as “*the study of being*” and concerned with “*what is*”, concerning the nature of phenomena or social ‘reality’. In this thesis, my ontological perspective is situated within a relativist ontological position. Relativism assumes that there is no objective truth; instead knowledge was created through subjective interpretation and social interactions (Crotty, 1998). Guba (1990) asserts that realities:

“exist in the form of multiple mental constructions, socially, and experientially based, local and specific, dependent for their form and content on the persons who hold them.” (Guba, 1990, p. 27)

I have come to understand that there is a common, shared, context-dependent and subjectively perceived ‘reality’, and I reject the option that social behaviour is governed by ‘laws’ that are fixed, independent of reality and generalisable. In this study, women’s experiences of heart disease and attending a CR programme are assumed to be influenced by women’s sociocultural locations. Other influence to be taken into account include: a) social interactions with family members, b) healthcare professionals and c) other patients. In this thesis, I have situated gender as a social, rather than individual category, which is relational and shaped by culture or situated. Therefore, in order to address the research questions, a relativist ontology supports this study.

A related but different concept, epistemology is the study of the nature of knowledge, including what kinds of knowledge are possible and what is regarded as acceptable knowledge in a discipline (Crotty, 1998; Bryman, 2016). Epistemology involves dealing with “*how we know what we know*” (Crotty, 1998, p. 8). According to McHugh and Cosgrove (2002), an epistemological framework specifies not only what knowledge is and how to recognise it, but who are the knowers, as well as the ways someone becomes a knower or expert.

The epistemological stance supporting this research is 'social constructionist'. The broad premise of constructionism is that human beings are continually constructing social phenomena, and their meanings; therefore as an individual engages with the world he or she is also trying to make sense of it (Crotty, 1998; Bryman, 2016). Therefore, social constructionists assume social reality is not a fixed, factual entity that exists independently from human beings, and rather it is socially constructed through sustained social interactions and relationships (Gergen, 1999, p. 3). From the perspective of constructionists, women and men think and act in the ways they do not because of their role identities or psychological traits, but because of the concept about femininity and masculinity that they adopt from their culture (Courtenay, 2000). Greenwood (1994) highlights,

"Social realities, therefore, are constructed and sustained by the observation of the social rules which obtain in any social situation by all the social interactors involved... Social reality is, therefore, a function of shared meanings; it is constructed, sustained, and reproduced through social life." (p. 85)

Similarly, Schwandt (1994, p. 118) argues that "people give meaning to reality, events, and phenomena through sustained and complex processes of social interaction". From this perspective, gender is viewed as a dynamic, social structure. A focus on the interactionist and relational aspects of meanings, therefore, underpins this thesis, which aims to understand women's experiences of living with heart disease. It is assumed that in describing their experiences, women have constructed different social realities which portray multiple dimensions of their lives, such as their interpretation of sociocultural expectations, their social relationships, and their daily experiences with heart disease. Under these realities, a similar experience can be interpreted differently by the people involved (West and Fenstermaker, 1995). Adopting social constructionism_researchers acknowledge that they do not stand outside the research field, but that they bring their own background to shape their interpretation of what is before them, as they import their own personal, cultural, and historical experiences into the research process (Creswell, 2013).

3.4 Methodology

According to Crotty (1998), methodology refers to both a theoretical approach and / or a plan of action. In this section, the methodology used in this study to answer the

three research questions is presented. Referring to the overall aim of this research, it requires a research approach that facilitated the exploration of women's experience(s). Feminist-informed qualitative research is suitable for this. In this section, I start by a brief overview of feminist methodology, before I present my justification and rationale for the choice of the research design employed in my thesis.

3.4.1 Feminist methodology

Much of the ongoing debate in feminist methodology literature stems from the queries relating to whether there is a distinct feminist methodology. Ramazanoglu and Holland (2002b) noted that there is no single agreed way to do feminist research. They argue that the primary purpose of conducting feminist research is neither to attain political accuracy nor methodological purity, but to provide insights into the area of gendered social existence that is frequently ignored. Feminist methodology is based on the groundwork of feminist theories and multiple constructions about women's perspectives of oppression (Holloway and Wheeler, 2010).

Multiple authors have written extensively regarding whether a study can be categorised as a feminist study, or not (Campbell and Bunting, 1991, Demarco et al., 1993, Duffy, 1985). Ramazanoglu and Holland (2002a) stated,

“Research projects can be thought of as feminist if they are framed by feminist theory, and aim to produce knowledge that will be useful for effective transformation of gendered injustice and subordination.” (p. 4)

McDonnell (2009) emphasised that the focus of feminist theory is to understand and analyse women's positions in society. Ramazanoglu and Holland (2002a) claimed that what is essential when doing feminist research is to understand the experiences of women and give voice to those experiences. Leavy (2014) emphasises that feminist research is not a static entity; instead, it is a transforming and transformative practice. Therefore, in this thesis, feminist methodology has been chosen to guide this investigation into women's lived experiences of heart disease and their enrolment and participation in CR programmes.

The main principles guiding this research correspond to feminist research, as defined by Duffy (1985) in that: 1) the researcher is a woman; 2) the primary purpose of the

research is to study women's experiences, and 3) the outcome of this research has the potential to help the participants as well as the researcher. In other words, feminist research is research on women and for women by giving priority to female experience (Wilkinson, 1986). It, therefore, depends on the development of a different relationship between researcher and researched from that in traditional approaches. This current research is also characterised by adopting a non-hierarchical relationship between the researcher and her study participants, expressions of feelings, and concern for values.

Intersectionality postulates that all members of society are located within the systems of social relations structured in dominance (i.e., class, gender, race, age, sexual orientation), even if references to those categories may not be explicitly mentioned by research participants (Cuadraz and Uttal, 1999). From an intersectional perspective, these multiple social relationships reinforce each other and shape individuals' life experiences (Crenshaw, 1991). However, despite the abundant number of theoretical discussions on intersectionality, the task of translating this theoretical call of intersectionality into methodological practice in inductive research faces a major methodological problem (Bilge, 2009). There are no clear methodological guidelines or standards for intersectional research.

Bowleg (2008, p. 11) argue, "the interpretative task for the intersectionality analyst is to make explicit the often-implicit experiences of intersectionality, even when participants do not express the connections". Therefore, in this research, I followed a two-step hybrid approach as outlined by Bilge (2009), in an attempt to combine intersectionality with inductive research methodologies. The first level of analysis involved data-driven inductive approach by using a framework analysis approach. Meanwhile, the second level of analysis was conducted during the stage of data interpretation, in which I incorporated the perspective of intersectionality by continually asking how each individual account was related to broader social relations structure in dominance and contexts (i.e., age, religion, gender, ethnicity) (Cuadraz and Uttal, 1999). During the first step, I focused on an analysis involving the identification of emergent themes from the interview transcripts. At the second step of the analysis, I tried to operationalise intersectionality as a lens to discuss the individual's account by articulating it around gender by asking the question: "*How*

gender interacts with other social categories? Which dimensions of the experience are interacting with gender?” (Bilge, 2009, p. 7)

3.4.2 Rationale for drawing on a qualitative research methodology

According to Flick (2014), the research approach chosen must reflect the best fit to answer the specified research questions. The main interest of this study is to investigate women's experiences with heart disease and CR participation; therefore, I used a feminist-informed qualitative research approach. Many feminist researchers prefer qualitative methods not only because qualitative methods have more affinity with the ideas of feminist, but also qualitative methods allow women to have a voice and to influence the conduct of research (Leavy, 2014). Feminists value the representation of marginalised groups, and the use of subjective and qualitative approaches to information gathering allows such participants to speak about their own experiences.

As suggested by Crotty (1998), a methodology needs to be relevant to the research aims, as well as consistent with the researcher's theoretical perspective, which in turn will inform the choice of the methods selected. Many feminists have always viewed qualitative research as more compatible and capable of being adapted to feminism's central tenet (Finch, 2004). However, Finch (2004) also noted that there is no single method for feminist research (see also 3.4.1 above); the paradigm chosen will depend on the research questions that need to be addressed. It is the idea that women's experience needed to be captured through the research process that consolidated the tendency for the adoption of a small-scale, qualitative, and intensely personal methodological preference. Holloway and Wheeler (2010) define feminist inquiry as research that

“Focuses on the experience, ideas, and feelings of women in their social and historical context.” (p. 258).

There are no specific methods for analysing data in a feminist approach (Holloway and Wheeler, 2010). The focus of a so-called ‘feminist approach’ to research, is arguably to give women the opportunity to voice their own concerns and interests (Holloway and Wheeler, 2010), as well as to improve the status and reality of women's lives (McHugh et al., 1986). In contrast to the positivist approach adopted in

conventional 'scientific' studies, feminist research has paid particular attention to the way that the values, biases, and assumptions of the researcher influence the research process. In this sense, feminist research rejects the possibility of an unbiased, objective position or "value-free research" (Levesque-Lopman, 2000, p. 105). Therefore, Kelly (1986) stated that within the feminist framework, the product could not be separated from the process. Thus, feminist researchers strive to conduct research in an open, collaborative, and non-exploitative way.

Feminist research puts gender at the centre of a research study (Leavy, 2014), with the researcher adopting a gender perspective regarding the social phenomenon under investigation (Holloway and Wheeler, 2010). In addition, feminist research also: i) assesses the gendered context of women's lives, ii) reveals gender inequalities, iii) empowers women, and iv) advocates for social changes (McHugh and Cosgrove, 1998, McHugh and Cosgrove, 2002). To this extent, feminist research is not as simplistic as research *about* women, but research *for* women. Equally, from a feminist perspective, it is generally accepted that the knowledge resulting from the research is to be used to make women visible, raise their consciousness and empower them (McHugh and Cosgrove, 1998, Holloway and Wheeler, 2010). Feminist researchers challenged the traditional empirical research model by investigating the impact and influence that the values, biases, and assumptions of researchers exert on all aspects of the research process. Rosser (2008) argues that the study of gender raises the issue of how context and values challenge traditional conceptions of objectivity.

Creswell (2013) defined qualitative research as exploring and understanding the meaning of individual or group experiences that are attributed to a social problem. Further, the primary purpose of that exploration is to comprehensively present the stories and experiences gained from a study's participants. Qualitative research also helps the researcher to discover meanings, experiences, and views from the research participants' worlds (Pope and Mays, 2006). In addition, the qualitative research model provides a rich, descriptive, valuable understandings of individuals' attitudes, beliefs, motivations, aspirations, and behaviours (Green and Thorogood, 2009). Another distinguishing feature of qualitative research is that instead of studying people in artificial or experimental settings, it studies people in their natural settings (Pope and Mays, 2006). Bryman (2016) identified three main features of qualitative research; the paradigm is: i) inductive, ii) constructionist, and iii) interpretivist.

Qualitative research offers opportunities for researchers to use open-ended questions; thus, it gives a chance for the researcher to build new evidence, facts, or even theories (Denzin and Lincoln, 2011, Flick, 2014). The process of data collection is flexible and sensitive to the social context in which the data are produced.

3.4.3 Incorporating reflexivity into the research process

While researchers aim to achieve an “emphatic neutrality” in the research process and interpretation of the data (Ritchie et al., 2014), social research cannot ignore the influence a researcher has on the social world being studied (Hammersley and Atkinson, 1995). Further, Ritchie et al. (2014) suggest that there is no completely ‘neutral’ or ‘objective’ knowledge if human researchers are involved. Finlay et al. (2003) assert that the feminist version of reflexivity is concerned about “unexamined power balances between participants and researchers” (p. 5).

According to Charmaz (2014), reflexivity includes the examination of how the researcher’s interests, position, and assumptions influenced his/her inquiry. Researchers are obligated to continuously consider their own values and prejudices that they bring into the research situation. It is for this reason that reflexive activities are now considered to be an integral part of the interpretative process; a part that cannot be omitted.

3.4.3.1 Examination of my positioning within the research process

Since I started the research process, I have been aware of the importance of reflexivity in the whole process of the research. As the research progressed I realised that myself, me the researcher, is a principal figure who actively constructs the collection, selection, and finally the interpretation of data. For that reason, allow me to explain briefly about my personal background that may directly and indirectly influence the decision made during the course of the research.

I am a Javanese Muslim woman, in my thirties. I was born and raised in a lower-middle class family during New Order era in Indonesia. Both my parents only accomplished primary school education. My mother was born in the 1960s, into a strict Javanese family. She lived in a big multi-generational family, and she never had any chance to pursue higher education, just because our big family believed that higher education was not necessary for a woman. Although, initially, she insisted on

continuing her education after she graduated from primary school and even asked my grandparents to grant her wish, but the pressure from the big family discouraged her from pursuing her dreams. She always said to me that her children should have a better life and future than her own, and education is one of the ways to achieve that. In the place where I grew up, not many women or even men continued their education to a higher level. Most of my friends in primary school only finished junior or senior high school, and only a very small percentage had the opportunity to pursue their education at the university level.

Although my mother gives me freedom to pursue education, she also always taught me to be able to perform the role of a “good woman”; which means to be a good wife for my husband and a good mother for my (future) children, whilst at the same time being a good daughter to my parents. Since I was a child, my mother has always taught me to be considerate (*peka*), particularly in household matters, as well as to be able to perform and master a set of household chores, such as cleaning, cooking, and washing: my domestic skill set. To be considerate means that I do not need to wait for someone to give me the order to do the housework, but as a woman I should always take the initiative to do the chores.

Having lived in Indonesia and in Java for most of my life, I took the impact of social and cultural understandings for granted. I started to become aware of the social and cultural background informing people’s behaviour when I travelled the first time to Scotland in 2012, to pursue my Masters degree. Have been living in Scotland for almost five years, I have realised that it was more than an academic experience for me; rather, it was more of a life experience. Through meeting and interacting with people from various countries as well, as becoming more familiar with the culture in the UK, I watched myself evolve in line with a continuous integration between myself as a Javanese Muslim woman, yet also a PhD student living in the UK. I started to grasp the social context around me, and it has influenced the way I see and interpret the world, my moral beliefs, my hopes, and even how I behave and feel about something.

Finlay (2002) points out that there have been changes in the conduct of qualitative research; one move being that it no longer seeks to eliminate the presence of the researcher. However, this poses a challenge for the researchers, requiring them to

use self-examination to draw on their personal disclosure as a catalyst for interpretations of data and to provide further insights (Finlay, 2003). When reflecting upon my role in the entire research process, one of the issues that concerned me was to what extent my own values, beliefs, and cultural background would influence the interpretation of the findings in this study? To what extent will my relationships with my participants affect the way they tell their stories to me? As an Indonesian woman myself, I was familiar with the cultural and gendered discourse espoused by the women in this study. The facts that I am a married Indonesian woman and that I speak the Indonesian language, positioned me as an insider to the women in this study.

I have never met with any of the women who participated in this study. The first time I came to the CR centre, I was both an outsider and a stranger to the women there. To get familiar with the setting, as well as with the women in the CR centre, I attended CR programme daily and followed the activities of the patients during the period of data collection (from June to September 2016). I introduced myself to them as a researcher that interested to learn about their experiences of heart disease as well as their attendance at CR programme. Furthermore, I also adopted an informal interaction with the participants in the CR centre, allowing them to discuss issues as if in a normal conversation. Daily interaction with the women, as well as sharing my personal biography with them helped to build rapport between the potential study participants and me. I tried to be as honest as possible with them regarding my background, my intention, and the reason why I was interested in doing this study. By adopting this strategy, I noticed that the participants were more relaxed in discussing their experience of living with heart disease as compared to when the interview conducted before establishing a high level of rapport with participants.

Following the feminist principles, I considered the women as experts regarding their experience of heart disease and CR participation. It is also essential that I endeavoured to incorporate a collaborative relationship between researcher and researched: "just two women having a discussion" (Reinharz, 1983). Therefore, I followed the recommendation of Oakley (1981) for interviewing women. The author proposed a participatory model that involves the researcher sharing aspects of her own biography with the participant. She argues that a more conversational and sharing approach is believed to invite intimacy, which avoids creating a hierarchical

relationship between the interviewer and the interviewee. Recalling my experience during fieldwork, my participants also often asked me personal-type questions. In response, I always tried to be as open as possible with them about my background. I also shared some of my personal histories with them when they asked about it. I felt that this kind of informal interaction not only helped me to build trust with my participants but also helped me to break down the power hierarchy between me as a researcher and the women that I interviewed. Building a non-hierarchical relationship with the participants is particularly essential within the feminist approach.

However, I still realised that there was a potential power imbalance between my participants and me, especially related to my nursing background, and my background as a member of the academic staff of a university. In contrast, the majority of the participants just had a high school education. Therefore, when the participants knew of my background, they started asking questions about their condition and considered me as an expert. In response to this, I generally explained to them that I was speaking to them in the context of a researcher, and not a nurse, so I could not advise on their health. Typically, I referred them to ask the doctor or nurse in CR because I was not in the position and capacity to tell them what to do, even though I knew the answers to their questions. I also explained to them that I was very interested in understanding their personal experiences with heart disease, about which they were more knowledgeable than I was. I also chose to wear casual clothes instead of a uniform and used vernacular language during the interviews with the women, in order to minimise the potential of power imbalance.

To some extent, my background as an Indonesian woman gives me an advantage in a way that I was afforded a better understanding of many of the experiences of these women. However, I was aware that my personal experience of living abroad, in a very different social context, has influenced the development of my personal morals and perspectives. Therefore, despite considering myself an insider in relation to the sociocultural context of the women I interviewed, at the same time I considered myself as an outsider to their truths, perceptions, expectations, and relationships that influence their identities. As a Javanese woman I know my roles, my status, my position in society and I am proud that my mother always taught me to aspire to fill the role of being a good mother and wife. In this study, I can relate to my participants'

stories. Yet, I also had to acknowledge that I never had any personal experience of a cardiac event, and as such, I realised that I was unable to truly place myself inside the women's experiences. Nonetheless, I felt empathy with the participants. Therefore, my position in this research is that I am a young adult woman, from a proletarian Javanese family, with UK and Indonesian education backgrounds, who is influenced by Javanese values. My personal experiences, as well as my academic background as a nurse and lecturer, have directly and indirectly influenced my interpretation of the data in this study.

Overall, the prolonged engagement with the study participants helped me to collect detailed and rich data regarding their experiences. I believe that building trust is vital in any qualitative study, particularly those who adopt the feminist approach so that women feel comfortable to share their personal and private experiences.

3.4.3.2 Reflection on my study and my personal journey

I must acknowledge that this study was my first experience in conducting qualitative research. Prior to this study I attended several workshops and short courses in qualitative research; however, with my very limited experience in this area, conducting this PhD research was still a challenging experience for me. I was surprised by the extensive amount of the data. I also struggled during the process of coding and analysis. I was unsure how coding worked; hence in the beginning, I coded every line of my interview transcripts not knowing which one is important. This was a fundamentally important issue for me and it took me a while to understand what coding involved. With the help of my supervisors I was able to refine my coding and develop my thematic framework.

My interest in the cardiovascular area began when I was in my undergraduate degree; I took an internship in an Intensive Cardiac Care Unit (ICCU) for ten weeks, in 2009. However, since I started to work in the university's department of community nursing in 2010, I had not pursued this area any further. A few years back, I was involved in a cardiovascular taskforce initiating a cardiovascular centre in one of Indonesia's academic hospitals. Since then I have been very much attracted to the cardiovascular area again; in particular, the area of rehabilitation. There is still a scarcity of research on CR in Indonesia, possibly due to the limited availability of services that offer CR programmes. Also it should be noted that the focus of many studies was still towards

the biomedical aspects of the patients. To my knowledge, there has been no study carried out in Indonesia that explored patients' experiences of a CR programme. Even though I have a nursing background, I was often told by CR staff during my data collection that they were impressed by my enthusiasm for my chosen subject; as such, they often questioned me about how I knew about CR. Following the literature review, I became more familiar with CR and how women's participation is presented in the literature as a problematic issue. For this reason, I decided to further explore the matter of women's participation in CR programmes in the Indonesian context.

Before conducting this study, I had assumed that women would be reluctant to attend CR programmes due to their domestic duties, but surprisingly the women who attended the programmes did so in order to be able to resume to their social roles in the family and society as soon as possible. Additionally, I thought that the findings of this research would be unique and different from previous studies. However, I found that the experiences of the women in my study are similar to those found in other settings. It is arguable that my study's findings are relevant to the research outcomes from work in other countries as well. In terms of the process of the research journey, I have come to learn that it is important to have written everything down. Many times, during the early stages of my research I had ideas, read something important, or met somebody interesting, only to either forget important information or lose it. As I progressed through the researcher experience, I took the time to record my thoughts, and to write references down immediately after citing them. In doing so, I found it helpful to organise references using a software references manager.

3.5 Research Methods

This section explains the research methods employed in this study to meet the aim of this study. I provide an explanation of the research setting, gaining access to a research setting, participants' recruitment, as well as the process of data gathering.

3.5.1 The Study Setting

This study was conducted in the National Cardiovascular Centre (NCC), Harapan Kita Hospital, Jakarta, Indonesia. The NCC, which is governed by the Ministry of Health in Indonesia, is the largest specialised hospital in cardiovascular disease in the country, with a total bed capacity of 331. As a national referral hospital, NCC serves patients

with CVD from all over Indonesia; which was one of my main reasons for choosing this hospital as the research site. Conducting my study in this hospital gives me an opportunity to recruit nation-wide participants from various social and cultural backgrounds.

My research focuses exclusively on women's attendance of phase two outpatient CR programmes. Therefore, I carried out my research in the outpatient cardiac rehabilitation unit within the Department of Promotion, Prevention, and Cardiac Rehabilitation of NCC. Due to the limited CR capacity, only those patients who had undergone cardiac surgery were eligible to be referred to the phase two CR programme in this hospital. Specifically, the insurance scheme from the government only covered the CR fee for patients who had undergone cardiac surgery. Hence, during my data collection, I did not meet any patients who had not experienced cardiac surgery; all participants attending the CR programmes I studied were post-operative.

In the NCC, a CR programme is divided into three phases. Phase one takes place during the acute phase of the illness, starting at the pre-operative stage. Few days before the cardiac surgery, a physiotherapist or nurse approaches the patients to provide general information regarding their disease, its causes, as well as to teach patients about pain management during the post-operative stage. A few days after the surgery, a physiotherapist or nurse revisits the patients and assists them to perform early mobilisation activities. Following that, usually five days after the surgery, CR staff will take patients to the CR unit to introduce and orientate them to the programme. During this first visit to CR, patients will receive interdisciplinary patient education and information related to the CR programme. In addition, at this time CR staff will also obtain data on each patient's level of fitness, to determine the duration, intensity and frequency of the exercise dose, by using a six-minute walking test and telemetry monitoring.

This hospital implements early enrolment; thus, the phase two CR programme starts as soon as the patient is discharged from the hospital. The exercise programme is individually prescribed by physiotherapists or other CR staff, based on the physical condition of each patient. In total, a phase two CR programme consisted of twelve exercise training sessions, with one-hour duration for each session, and delivered within a period of two weeks to two months. Apart from the exercise programme,

patients are also invited to attend educational and counselling sessions. Patients who reside outside of Jakarta could attend the rehabilitation programme in daily mode, in which patients attend their CR programme every day (Monday to Friday) for two weeks.

On the other hand, patients who live in Jakarta are scheduled to have three meetings per week. At the patient's last meeting, the staff will evaluate the patient's exercise capacity through a repeat of the treadmill exercise test. The patients then will receive a certificate to confirm their completion of the CR programme. Patients who are willing to continue their exercise programme can enrol in a phase three programme in a home-based or community-based setting.

3.5.2 Gaining access to a research setting and study participants

Gaining access to a research setting and participants can be onerous, time-consuming, and is not a single event (Holloway, 2005; Larkin, 2013). Approaching participants in this study involved approaching various levels of gatekeepers. Pragmatic considerations are important to any research study and my role as a lecturer in an Indonesian-based university facilitated negotiations with the hospital gatekeepers in providing access to the organisation and possible participants. In this section, I explain the process I undertook to access the research settings and also the research participants (Figure 3.1)

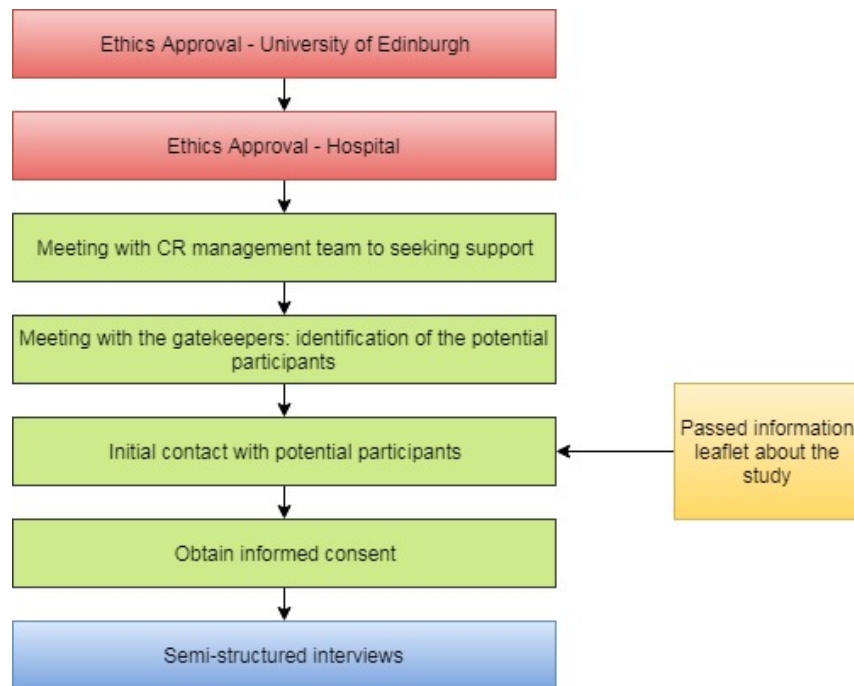


Figure 3.1 Gaining access and recruiting participants

Before collecting the data, the first step was to seek ethical approval from the Research Ethics Committee at the University of Edinburgh, who agreed that the research topic was necessary. They formally approved the research on 26 May 2016 (Appendix 2). The second step was to seek ethical approval from the Research Ethics Committee at the Jakarta hospital. To negotiate access to the hospital was a long process. Initially, I contacted the research ethics committee by phone on March 2016 who then asked me to send the complete research proposal and application letter for ethical review. By the end of April 2016, I received an email confirming that the ethics committee had received my application. Following that, they requested me to provide for more supporting documents, included brief protocol of the proposed study, research ethics application, participant informed consent and information sheet, interview guideline, researcher's curriculum vitae, and ethical clearance from the university if available. After they received my supporting documents, they sent me another email scheduling for a Full Board Review or presentation in front of the hospital's research ethics panels on May 12th, 2016.

About ten members of the Ethics Committee were present in the board review. During the review, the committee members asked for some clarifications on the research design and suggested some alterations on the research methodology and methods,

including the suitability of qualitative research, the number of participants, and the data collection method. There were several amendments that were required to be made to the initial ethical approval application and these were made following consultation and advice from my supervisors. Ethical approval was granted on June 17th, 2016.

3.5.3 Recruitment of the participants

Following the approval of the study by the Ethics Committee at the hospital, I met the head of the Department of Promotion, Prevention, and Cardiac Rehabilitation to explain about my study and seek for her endorsement. She welcomed the prospect of the study and asked me to prepare a presentation about my research at the department's morning meeting. As has been noted in the literature, CR staff in the NCC consist of a multi-disciplinary team, including cardiologists, nurses, physiotherapists, occupational therapists, psychologists and administrative staff. Most of the staff attended the morning meeting; to them I explained the aims of my study, the plan for data collection, as well as the enrolment criteria for the participants.. After presenting my study, I got the impression that the staff in the CR thought it was an important study. Some of the staff were surprised about my research interest in CR, and so asked me how I learned about the issue of CR.

After this meeting, I met the manager of the CR programme and two nurses who agreed to be the gatekeepers of my study to discuss further the recruitment procedure. They helped me to familiarise myself with the CR setting and environment, as well as provide some general information about the CR programme being offered at the NCC. They explained the structural organisation in the Department of Promotion, Prevention, and Cardiac Rehabilitation, the eligibility criteria for the patients referred to the CR, the flow of the patients at CR unit, as well as many other issues.

We began the task of identifying potential participants by reviewing the registrar books which consisted of the lists of the patients referred to, and enrolled in, the CR programme, as well as the patients' medical records. Furthermore, the gatekeepers also distributed leaflets containing brief details about the study to the CR participants (the leaflet can be seen in Appendix 7). The patients' records were also used to identify potential participants because they provided information on: a) the patients'

history of the heart disease, b) treatments, and c) sociodemographic details of the participants, including their contact number and address. Having identified some potential participants from the registrar books and patients' records, the nurses who were acting as the gatekeepers approached the patients about the possibility of participating in the study. At this stage, an information package including the participant information sheet with details about the study (Appendix 4), invitation to participate (Appendix 6) and the consent form (Appendix 5) were provided to potential participants in the CR unit. If the potential participants indicated an interest, the gatekeeper directed me to meet them so that I could provide more information regarding the study. I then met the potential participants to explain more about the study at the scheduled time. Potential participants had the opportunity to seek clarification and ask questions. When I was assured that they understood the information, I asked them whether they remained interested in taking part in the study or not. When potential participants expressed interest verbally to participate in the study, an appointment was made for a face-to-face research interview.

At the start of the research process, I was hoping to recruit both those patients who participated and those who did not participate in the CR programme. However, the collection and identification of the sample of the women who did not participate in the programme proved to be exceedingly difficult. Initially, I planned to obtain the data of the participants who were referred to and did not attend or dropped out from the programme by identifying the patient record in the last three months prior to data collection (March, April, May); once identified I would invite them by telephone to participate in this study. Unfortunately, the record of the patients in the CR centre was poor, as it was done manually. To identify the potential participants, I relied on the hand-written, registrar books consisting of the list of the patients who had been referred to the programme (see Figure 3.2). During this manual identification, I recorded six women dropped out in May, two women dropped out in April, and none dropped out on March, or perhaps were just omitted from the registrar book. Unfortunately, I could not identify which patients did not attend the programme. I confirmed this to the person in charge of patient registration in CR, as well as the CR supervisor, but they also could not give much help to identify patients who failed to attend CR. I decided to contact the eight women who dropped out of the programme by telephone, and only three of them agreed to be interviewed. For this reason, I had to change the direction of this study to focus only on people who do decide to

participate in the CR programme, to understand 'what makes it work', rather than those who do not.

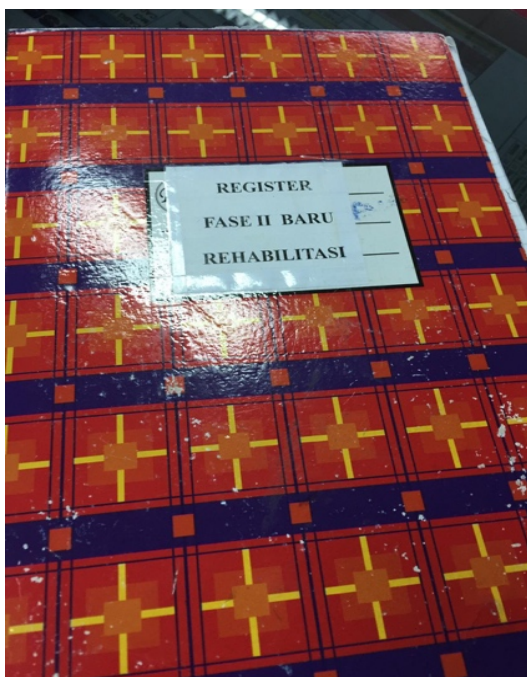


Figure 3.2 CR Registrar book

3.5.3.1 Study sample

A purposive sampling strategy was adopted to select study participants in this study. I used this sampling strategy because of its flexibility to meet the purposes of the study. Purposive sampling facilitated the researcher to select participants who could provide information that was relevant to the research questions (Bryman, 2016). Specifically, I used the pragmatic approach of a maximum variation sampling strategy to select a diverse sample of women (Patton, 1990, Polit and Beck, 2008). Such a sample would provide a wide variety of perspectives regarding gender roles and norms from women across different social settings.

The criteria for selection of the participants were women who: i) women who were over 18, ii) had experienced a 'cardiac event', iii) had been referred to in a phase II CR programme. There was no limitation concerning the participant's diagnosis and age. Thus, this study included women who had experienced various forms of heart disease, including 13 women with congenital issues (atrial and ventricular septal defect and tetralogy of Fallot) and 13 others with coronary heart disease. Nevertheless, all participants in this study had experienced a serious cardiac event

resulting in CABG, angioplasty, or other medical intervention such as a valve replacement, within the three months prior to data collection. In addition, all the participants experienced a waiting period of between three months to a year before they received their cardiac surgery. Women who did not have the mental capacity to give informed consent, or women with severe breathing or verbal communication problems, and who were therefore unable to commit to an interview, were excluded from the study.

The women who took part in this study were varied, in terms of age, education level, ethnicities, working situations, marital status and their sociocultural backgrounds. The age range of the participants was from 30-67 years old, with a mean age of 46.7 years. All participants had initially enrolled in the phase two CR programme within the three months before the researcher approached them, although five of them later dropped out of the programme. Based on the ethnicity, the largest proportion of women in this study was Javanese, who constituted almost a third (30.77%) of the total participants. The second largest groups were Sundanese and Minangkabau, both with 15.38%. The remaining participants came from various ethnic groups, such as Batak (7.69%), Betawi (7.69%), Minahasan (3.85%), South Sumatran (7.69%), Sasak (3.85%), East Nusa Tenggara (3.85%), and Banjarese (3.85%). Twenty-five participants in this study were protected by the government insurance scheme that covers all medical costs including the CR fee; only one participant attended the CR programme on a self-pay basis. In terms of educational levels, the majority of the participants had a high school degree (61.53%); three participants had only received primary school education, and four were university graduates. Details of the participants interviewed are outlined in Table 3.1.

Table 3.1 Biographical data of participants

No	Pseudonym	Age	Ethnicity	Marital status	Occupation Status	Level of education
1	Ratri	44	Sundanese	Married	Full-time	Senior high school
2	Lilis	41	Sundanese	Married	Part-time	Senior high school
3	Manurung	66	Batak	Widowed	Part-time	Junior high school
4	Dju	62	Betawi	Widowed	Part-time	Senior high school
5	Raline	32	Betawi	Divorced	Unemployed	Senior high school
6	Susan	44	Javanese	Married	Unemployed	Senior high school
7	Ori	43	Sundanese	Married	Full-time	Senior high school
8	Meli	36	Minahasan	Married	Unemployed	Bachelor degree
9	Lisa	54	Javanese	Widowed	Unemployed	Senior high school
10	Sari	44	South Sumatra	Married	Unemployed	Senior high school
11	Ningsih	33	Javanese	Married	Unemployed	Senior high school
12	Rosi	61	Minangkabau	Widowed	Retired	Senior high school
13	Lani	58	West Nusa Tenggara	Widowed	Part-time	Junior high school
14	Regina	53	Javanese	Married	Full-time	Bachelor degree
15	Desti	36	East Nusa Tenggara	Married	Unemployed	Bachelor degree
16	Diana	42	Batak	Married	Part-time	Junior high school
17	Hana	36	Sundanese	Married	Unemployed	Bachelor degree
18	Norma	30	Javanese	Married	Unemployed	Senior high school
19	Dirga	30	Javanese	Married	Unemployed	Senior high school
20	Titi	36	Javanese	Married	Full-time	Senior high school
21	Nourah	58	Minangkabau	Married	Part-time	Primary school
22	Ambar	46	Banjarese	Married	Part-time	Senior high school
23	Sisi	67	Minangkabau	Married	Retired	Senior high school
24	Eva	58	Minangkabau	Married	Unemployed	Primary school
25	Lastri	55	South Sumatra	Married	Full-time	Primary school
26	Nona	49	Javanese	Married	Unemployed	Senior high school

3.5.3.2 Informed Consent

I informed all potential participants both verbally and through information packs about the overall purpose of the study, data collection methods, the likely risks and benefits that could be incurred, use of the results and the reporting system. By providing this detailed information, it assured my participants that I did not want to 'coerce' or 'deceive' them, as well as helping me to obtain their informed consent (O'Neill, 2003). After receiving adequate information, the potential participants were free to withdraw from the study at any point without explanation or to continue their participation in the study (Gerrish and Lacey, 2010). Therefore, when approaching potential participants, I made it clear that they had the right to refuse to participate in this study, without them being worried about any consequences. An information sheet should provide information about confidentiality, participants' voluntary participation and their right to withdraw from the study at any time (Kvale and Brinkmann, 2009). Therefore, I clearly stated in all the information sheets that participation was voluntary and participants could withdraw from the study anytime. If the participants agreed to continue their participation, I asked for signed consent from all the women who agreed to continue their participation in the study, before the in-depth interviews took place. However, another approach was taken to obtain consent from the participants who were invited to participate in this study over the telephone. A phone call on behalf of the clinic was made. During this call, the information regarding the study was explained verbally to the potential participant. They were then given the time to decide whether they were interested in participating in the study or not. Participants were given the option to call back to the clinic or chose a time where we could make a follow-up call. If they agreed to participate, prior to the interviews, I asked for verbal consent from them.

3.5.4 Data collection methods

The literature demonstrated there were several different methods for collecting and analysing data in nursing research. This section describes the method of data collection in this study and how it was implemented. In total, twenty-six participants were interviewed: twenty-three face-to-face and three by telephone. I conducted the interviews no earlier than the sixth session of their CR programme, to allow the participants to become familiar with their CR setting. It should be noted that the women who previously agreed to participate, but then decided to drop out, were not interviewed. The duration of the interviews ranged from 15 to 75 minutes. Face-to-

face, in-depth, semi-structured interviews were conducted within the hospital premises at a date and time, which was entirely the participant's choice. I conducted all interviews in the Indonesian language, which I then transcribed verbatim. I used an interview guide, with broad open-ended questions, because this method gave structure to the interview and ensured that the same general topics were discussed with each participant (Appendix 12 and 13). The interviews focused on the participants' cardiac experiences since diagnosis, changes in their daily lives following the diagnosis, the influences on their decision to participate in the CR programme, barriers and facilitators for participation, and participants' current circumstances.

3.5.4.1 Semi-structured interviews: face-to-face and telephone interviews

The data collection methods used in this study were semi-structured, face-to-face interviews and telephone interviews. Bryman (2016) highlights that interviewing is a valued method of data gathering within a feminist research framework. It offers flexibility for the researcher to gain an understanding of the lives and experiences of participants (Leavy, 2014). Rubin and Rubin (2012) highlight the power of in-depth interviewing to illuminate research topics:

"When using in-depth interviewing... researchers talk to those who have knowledge of or experience with the problem of interest. Through such interviews, researchers explore in detail the experiences, motives, and opinions of others and learn to see the world from perspectives other than their own." (p.3)

Feminist researchers are frequently interested in women's experiences that are hidden (Geiger, 1990). In-depth, semi-structured interviewing was undertaken in this study to facilitate and encourage the women to share their thoughts, feelings, beliefs, and experiences using their own words. In this study, I wanted the women's voices and their stories to be heard. The use of semi-structured interviews also gave me the opportunity to probe deeper via questioning, and to explore more fully, depending on the participant's response. In addition, field notes were written soon after the interview in order to capture context, such as the participant's behaviour during the interview, or my thoughts and feelings in relation to the interview process.

Green and Thorogood (2009) stated that interviewing is designed to obtain the lived experience of the participant. However, not all types of interview are suitable for a feminist approach. The feminist interviewing ideal is aware of the relationship between the interviewer and interviewee, and of the ways that power operates in the interview and (in) the product of the research. Bryman (2016, p. 488) highlights some essential elements for conducting feminist interviewing, which include “a high level of rapport between interviewer and interviewee, a high degree of reciprocity on the part of the interviewer, the perspective of the women being interviewed, and a non-hierarchical relationship”. I tried to ensure my research was conducted as a mutually collaborative endeavour, with the women as partners in the research process. Mutuality was mediated in the way that I did not interact with participants for the sole purpose of data collection.

It was essential to establish a relationship of trust with the participants so that they would feel comfortable talking about their experiences (Streubert and Carpenter, 1995). For this purpose, I adopted an informal interaction and prolonged engagement with the participants in the CR centre, allowing them to discuss issues as if in a normal conversation. Therefore, before conducting the interviews, I followed their activities for several days in the CR centre to be acquainted with the women and what they were doing. By adopting this strategy, the participants were more relaxed in discussing their experience of living with heart disease as compared to when the interview conducted before establishing a high level of rapport with participants.

Researchers have observed that a lack of trust could be an issue in interviewing women (Finch, 1993). It happened to me when I interviewed a woman where I had not had an opportunity yet to have informal interaction with her before the interview. At that time, the nurse who helped me to recruit participants scheduled an interview with a participant with whom I had not yet had time to build much informal interaction. As I anticipated, the interview was shorter than usual because I had a feeling that the participant did not trust me yet at that point. Thus, she tended to give me short answers to the question I asked during the interview. From that experience, I learned that building a high level of rapport with the participant is the key success of interviewing women.

I was aware that telephone interviewing has been criticised for leading to a lack of trust, inability to probe, possible deception and, until Skype or i-phones, a lack of visual, non-verbal feedback (Novick, 2008). However, since a face-to-face interview was not always possible, for instance due to geographical constraints, I decided to conduct telephone interviews to gather data from participants who did not attend the programme at all or who dropped out. Telephone interviews are useful if the research needs a population that is not geographically concentrated, or not close to the researcher in physical distance terms (Oltmann, 2016). More importantly, considering the travel cost and time constraints, I did not have the resources to reach the participants in person, in order to conduct a face-to-face interview.

Although the previous study Sturges and Hanrahan (2004) suggested that both face-to-face and telephone interviewing generated the same quantity of data and no difference in the nature and depth of participant responses, I realised that this method of data collection has several limitations. Abdal (2015) in her research with Kuwaiti women also collected her data through telephone interviews. She noted that building rapport was not a problem and her female participants were also more comfortable to share intimate information during their telephone interview than they would have been face-to-face. However, this is not the case in my study. Difficulty to build rapport with the participants became the central issue using telephone interviews. I noticed that the women that I interviewed via telephone tended to give short answers. This issue was almost certainly because I had not met them face-to-face prior to the telephone interview; to them I was a stranger. In Abdal's study, the telephone interview was her second approach meaning that she had a chance to meet with the women face-to-face before interviewing them over telephone. Another critical limitation about my telephone interviewing was, as pointed out above, I could not obtain any visual cues, so I was unable to explore the body language of the participants. Of the many calls that I made, three participants agreed to be interviewed by telephone. I recorded the interviews with permission from the participants. The duration of the telephone interviews lasts from 15 to 50 minutes.

Based on my experience, it was apparent that building trust with the participants who were contacted by telephone was much more challenging than with those who had a face-to-face interview. Having to deal with this situation, I tried to be honest

and open with them regarding the purposes of the call and the interview. I told them that I was interested in learning their recent experiences with heart disease and their participation in their phase two cardiac rehabilitation programme. I also explained the estimated duration of the interview and emphasised that they have the freedom to accept or refuse my invitation. Some of them directly refused my invitation stated they were not interested, whilst some agreed to participate in my study and to be interviewed. Before we started the interview, I asked the participants' permission if it was okay for them to have their interview audio-recorded.

I remembered I was feeling very nervous during my first few interviews with the women. However, after a couple of interviews, I gained more confidence so that I was able to adopt a more relaxed approach. For example, I referred to the interview guide much less than I had in the first few interviews. I used open-ended questions so that participants able to answer the questions in their own words, and to elaborate as they wished. At the end of each interview, I allocated approximately 10 minutes for a debriefing, by asking the interviewee if there was anything else she wished to add (Kvale, 2007).

3.5.4.2 Data Management

Organising the data was one of the first steps in data analysis, to facilitate working through the data systematically. According to Spencer et al. (2013), data management refers to the process of: a) creating 'manageable' qualitative data; b) of labelling and sorting the data according to a set of themes or concepts before c) moving to the next level of more interpretative analysis.

I recorded the interviews using a digital voice recorder. Recordings were transferred from the digital recorder to a password-protected computer immediately following each interview. I transcribed each interview verbatim, as soon as possible following each interview. Once completed, each of the interview transcripts was then entered into NVivo 11, which is a CAQDAS (Computer Assisted Qualitative Data Analysis) programme. CAQDAS offers access to a range of powerful research tools for indexing, retrieving, organising, and note-taking that can assist in the process of data analysis (Fielding and Lee, 1998). Pseudonyms for the sake of participant anonymity

were applied to the interview data at the point of transcription and all references to specific places of people were replaced to retain anonymity.

3.5.4.3 Translation

As suggested by Twinn (1997), the quality of the data could be maximised if the analysis was done with the source language. This point is similar to the observation made by van Nes et al. (2010) who also suggested researchers should stay in the original language for as long and as much as possible during the data analysis. I believed that if I had only used translated transcripts to carry out the analysis, some of the original meaning might not be conserved. Therefore, the data analysis of this study was done using the original Indonesian transcripts. I translated from Indonesian into UK English in the later phases of the study, specifically during the process of writing up of the quotations in the finding chapters.

In examining the influence of translation on qualitative research, Twinn (1997) noted that the accuracy of the translation process is critical to the integrity of the results obtained in any cross-language research; a point of particular relevance when social context is an integral part of the data analysis. This study required a process of translation because the interviews were conducted in the Indonesian language, where I shared my respondents' language and culture. Since I am a bilingual speaker, and my mother tongue is Bahasa Indonesia (Indonesian language), as well as being familiar with the sociocultural and professional context informing this research, I did the translation myself. All the translations were checked by an Indonesian colleague who was fluent in both Bahasa Indonesia and English, and who also had experience working with qualitative interview transcripts. Back translation from English to Bahasa Indonesia was also conducted to ensure that there were no changes in meaning caused by the original translation process. Translation is one of the biggest challenges in any qualitative cross-language research, so if it is not addressed appropriately missed errors could threaten the trustworthiness of the data (Squires, 2009). This study involved the use of two languages; the interviews were conducted using Bahasa Indonesia as a source language, whilst the findings were reported in English. Taking advantage of being a bilingual researcher, the potential danger from misinterpreting participants' communications has been minimised (Esposito, 2001). Nevertheless, translation challenges were evident throughout the analysis, at different stages of the research process.

At the beginning of the data analysis, I translated five interview transcripts into English to facilitate the discussion of the findings with my supervisors. Al-Amer et al. (2016) highlighted the challenges encountered in translating research findings from Arabic to the English language at different stages of analysis, including understanding metaphors and translating verbatim quotes. In my study I experienced the same difficulties. During the interviews, my participant frequently used a metaphor that was language specific. If I translate that metaphor word-for-word, the English translation may not be immediately understandable or entirely suitable to express the speaker's intended meaning. For example, my participant said: "*A housewife is the spine of the family*". This statement expresses a metaphor in the form of idiom that is specifically bound to Indonesian culture and signifies the critical role of a wife in the family; or a person who is fully responsible for the lives of the other family members. In an attempt to avoid the loss of meaning, I provided fluid descriptions of meaning using various English formulations rather than using literal one-to-one word-translations. However, when I carried out analysis in the translated transcripts, I felt that some of the emotions and feelings expressed by the participants were lost because the conversation had to be fitted into the English structure. Therefore, I decided to carry out the data analysis in the original Indonesian language.

3.6 Data analysis

Thorne (2000, p. 68) explains qualitative analysis as "the most complex and mysterious of all of the phases of a qualitative project". Reflecting on my first experience of conducting qualitative analysis, I concur with that view. Despite the lengthy process I took to immerse with the data through the laborious familiarisation process, I still struggled to articulate and interpret the many interesting findings within the data.

In this study, I adopted the framework analysis method developed by Jane Ritchie and Liz Spencer at the National Centre for Social Research in the UK, in the 1980s (Ritchie and Spencer, 1994). This approach shares a similar analytic path to the thematic analysis model described by Braun and Clarke (2006); with the additional steps of data summary and display. The framework method employs: i) sifting, ii) indexing, and iii) sorting qualitative data in a systematic manner, in order to allow key issues and themes to emerge (Ritchie et al., 2014, Gale et al., 2013). Framework

analysis provides a structured and rigorous process of data management, whilst simultaneously offering the flexibility associated with qualitative research (Swallow et al., 2011).

The 'framework' label originated from the thematic framework, which is used to organise data (Spencer et al., 2013b). The framework can be used for indexing, but its distinctive feature is that it forms the basis of a series of thematic matrices, in which each participant in the study is assigned a row and where a column indicates a separate subtheme. Data are then summarised by case and by subtheme, and the summary entered in the appropriate cell. This matrix-based format allows the researcher to move back and forth between different levels of abstraction without losing sight of the raw data. Also this procedure facilitates both cross-case and within-case analysis (Spencer et al., 2013b). This approach appealed to me because I was a novice qualitative researcher with no prior experience of carrying out a qualitative study. The framework model provides clear steps and structures to follow in the ways of categorising and organising what initially seems like unwieldy qualitative data. In addition, comparing and contrasting data is vital to qualitative data analysis, in order to generate full descriptions to explain the phenomenon under investigation. This framework method greatly facilitates data comparisons through the review of data across the matrix.

The framework method is not attached to any particular theoretical or epistemological position (Gale et al., 2013). Due to its flexibility, framework analysis can be applied to a variety of research interests and theoretical positions to facilitate the analysis of patterns or themes within the data (Gale et al., 2013). Ward et al. (2013) remarked, with regard to the development of themes, framework analysis is unlike grounded theory that is solely an inductive approach. However, the framework model also facilitates the abductive approach of qualitative analysis, which combines emergent themes, existing concepts and issues derived from previous literature (Gale et al., 2013). Therefore, the framework analysis method was selected in this study because it is suitable for addressing the research questions and overall aims of the study: i) to understand women's experience with heart disease, and ii) to access their experiences of participating in a phase II CR programme.

I followed the steps of the framework analysis approach, as outlined by Spencer et al. (2013a) (Figure 3.2), including a) familiarisation with the data, b) initial coding, c) developing an initial thematic framework, d) indexing and sorting the data, e) charting, f) mapping and interpreting the data. In the next section, I offer detailed explanations of each step taken in this analysis.

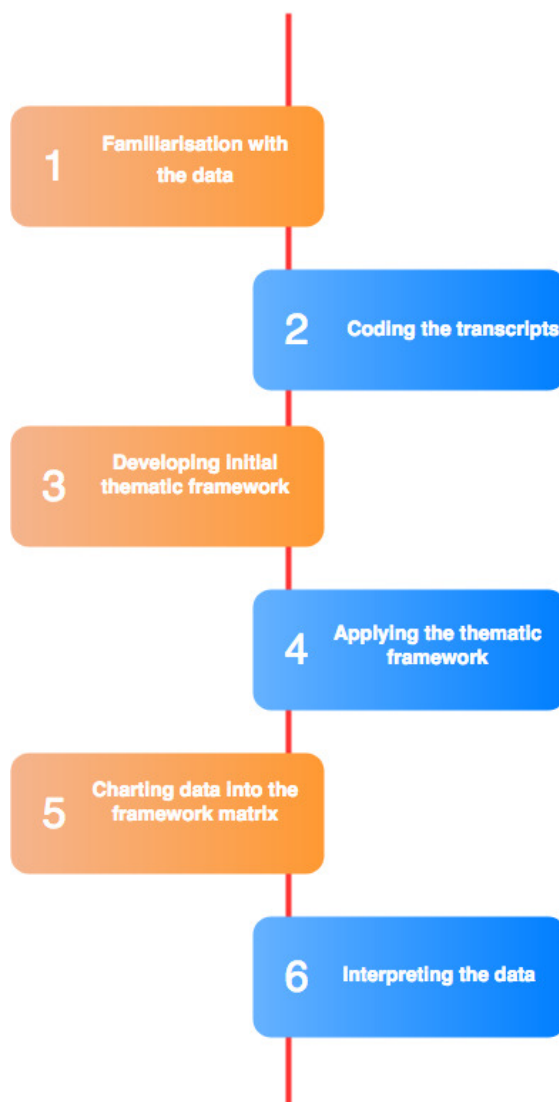


Figure 3.3 Analytic approach used for the study

3.6.1 Familiarisation with the interview data

According to Spencer et al. (2013a), the overall aim of the familiarisation process is to acquire an overview of the data and gain familiarity with the transcripts. It is the

process where the researcher gets to know the data in order to obtain a sense of what is going on. The actual process of my familiarisation with the data started as soon as the data collection began. At the initial step, I transcribed each interview verbatim. Following that, I checked the transcripts for error by listening to the audio-recordings of the interviews, whilst simultaneously reading the transcripts. The process of transcription was both exhausting and time-consuming but simultaneously crucial in gaining a close understanding of the participants' experiences in their cardiac journey.

Spencer et al. (2013a) stated that for the purpose of familiarisation within framework analysis it is not necessary to include all of the data. However, as the sample size was small enough, I included every transcript in the familiarisation process to ensure that no data were overlooked. To familiarise myself with the whole data set, I started by reading, and then re-reading, each interview transcript, while listening to the audio-recorded interviews. I found this process to be essential because it allowed me to become immersed in the data and facilitated the identification of emerging themes or issues. Following that, I worked with paper copies of the data and began to write down my initial ideas. At this stage, I identified interesting topics or issues that were recurrent in the data set and relevant to the research questions. In addition, five samples of the translated transcripts were also given to my supervisors to facilitate the discussion of the emerging topics, as well as to improve the rigour of the data analysis.

3.6.2 Initial coding

Saldaña et al. (2011) defines a code in qualitative research as

“...a word or short phrase that symbolically assigns a summative, salient, essence capturing, and/or evocative attribute for, a portion of language-based or visual data.” (p.4)

In qualitative data analysis, researchers use the code as a means of organising data for the latter purpose of facilitating the analytic process (Saldaña et al., 2011). After the familiarisation process, I carefully read the transcripts line by line, applying a code or label to any passage that I interpreted as meaningful. At this stage, I employed an open coding approach to ensure the important aspects of the data were not missed. I assigned codes based on the meanings that emerged from the data and the actual

spoken words of the participants ('in vivo' coding). I provided a sample that can be seen in Table 5.2. In the first set of interviews, I developed more than 200 codes because I considered everything as important and was scared of missing critical information. However, this process was lengthy, and I felt overwhelmed and lost in it. Acknowledging the fact that I was a novice researcher, it was an overwhelming experience trying to learn the basics of coding, using the software analysis tool, and carrying out qualitative data analysis simultaneously. Therefore, I took a step back and followed what Saldaña et al. (2011) suggested: "code on hard-copy printouts first, not via computer monitor" (p.29). I felt comfortable working with a paper and pen at the early stage of coding, as this basic approach really assisted me in gaining confidence, as well as having more control and ownership of the work.

After I finished with the open-code for five transcripts, I met my supervisors to discuss the codes that I had developed. We discussed each code that I had generated, as well as discussing each coded section in terms of why it had been interpreted as meaningful and how it might be useful for answering the research questions. This process was essential to ensure that my own perspective and subjectivity did not dominate the analytical process. Following this supervisor input, codes were grouped together into categories to form an initial thematic framework.

Table 3.2 Sample of open coding

Interview Transcript	Coding Labels
<p>S: Could you tell me what has happened to your life since then?</p> <p>M : What I felt at first, ¹because I used to be a person... I love to do everything ... such as sports the activity that I enjoyed the most in the past. ²Then I always go everywhere and do everything by myself, although I have a husband. For example, when I wanted to replace a lamp, or did something else, I did it by myself. ³But when I started to relapse in 2011, it was hard. I couldn't do anything like before. ⁴Even just to walk from here to there [the patient pointing from seat to the door approximately 1.5 meters], was already a struggle. ⁵So, after that I was totally dependent on my husband. ⁶Everything has changed since then. ⁷On top of that, we still had to look after the kids. They were still so small at that time; they were only one and two years old. ⁸Moreover, since they were babies we never asked our parents to help us with the kids. We did everything on our own. ⁹It was only recently because my condition has worsened and I had to do the treatment...so we asked our parents to help us with the kids. ¹⁰After that, I felt that the days had been so long.... During the last few years, I felt that time was running so slow and so long. ¹¹It was because...first, because I also had difficulty with sleeping... ¹²then I also couldn't do anything at home. ^{13 14}I was very dependent on my husband for everything and then I cannot take care of the kids. ¹⁵I mean, there were many things that I couldn't do like the old time when I was still healthy. Like before I gave birth to my second baby, when I was still pregnant, I was still able to teach English lesson to elementary school children in Manokwari, Papua. ¹⁶However, after the delivery, I was very ill, I could not do anything, I was totally confined to bed-rest. So yeah, everything has changed, indeed.</p>	<p>¹Used to be active</p> <p>²Independent</p> <p>³'World upside down', fluctuations and changes</p> <p>⁴Restriction of movement</p> <p>⁵Dependent person</p> <p>⁶Life transition</p> <p>⁷Difficulties in maintaining social roles and responsibilities</p> <p>⁸Independent, self-reliant</p> <p>⁹Condition to ask for help</p> <p>¹⁰Feeling frustrated</p> <p>¹¹Sleeping problem</p> <p>¹²Limitations in performing functional activities</p> <p>¹³Dependent person</p> <p>¹⁴Changing in family roles</p> <p>¹⁵Limitations in performing functional activities</p> <p>¹⁶Fluctuations and changes</p>

3.6.3 Developing initial thematic framework

The initial thematic framework is an essential step to organising data in a meaningful and manageable way for subsequent data analysis. According to Ritchie and Spencer (1994), both prior concerns and emergent issues arising from the familiarisation

process can be used to inform the process of developing framework categories. Therefore, the framework categories in this study were based on the key areas of interest outlined in the interview guide, as well as on the emerging issues arising from the process of familiarisation. I developed sub-categories under each main category to avoid ignoring or omitting data that did not fit. Each category was clearly defined so that it was apparent what information should be coded to that category and sub-category, so ensuring the consistency of the coding process. The categories and sub-categories that I developed at this stage were more descriptive and grounded in the data as the primary focus of this stage was on managing the data set, rather than data interpretation. Ritchie and Spencer (1994) emphasised that at this stage of research, a thematic framework is only tentative and the researchers have a chance to refine their work in the later stages of data analysis.

I found that developing a framework proved to be extremely time-consuming as it required several reiterations. After developing the initial framework, I piloted it to code three more interview transcripts in order to note any additional codes which did not fit the existing categories. I then met once more with my supervisors and, following discussions, revised the initial framework to incorporate new and refined codes. The process of refining and applying the thematic framework was repeated until no new codes were generated. I wrote a description for each sub-category to clarify its meaning, so that it facilitated the researcher's reviewing of existing codes, particularly when: i) creating new codes, ii) combining codes, or iii) creating sub codes of others. This process required both logical and intuitive thinking, as it involves making judgements about the meaning of each category, the relevance and importance of the issues, as well as the connections of the ideas between the categories (Srivastava and Thomson, 2009). The framework used in this study consisted of the following major categories:

1. Women's accounts of the first time getting their diagnosis
2. Description of the impact of heart disease on everyday life
3. Description of the strategies in managing heart disease
4. Description of women's motivations to attend CR
5. Description of the facilitators and barriers to CR participation
6. Description of women's future hopes and expectations

3.6.4 Indexing: applying the thematic framework

The purpose of this stage is to organise the interview transcripts into the framework categories before charting the interviews themselves (Ritchie and Spencer, 1994). I applied the initial thematic framework by indexing the remaining interview transcripts using the existing categories and codes. Indexing or coding involves the researcher labelling sections of texts, based on their understanding of what that section of text is about (Bazeley and Jackson, 2013). In this stage, I started to use the CAQDAS package (QSR NVivo version 11) because it speeds up the process and facilitates easy data retrieval in the later stages of the analysis. I assigned a number to each code for easy identification. The term 'indexing' is most commonly used rather than 'coding', because it was argued that this process more accurately captured the status of the labels and the way in which they 'fit' the data. Spencer et al. (2013a) also pointed out that indexing involves

“reading each phrase, sentence and paragraph in fine detail and deciding ‘what this about?’ in order to determine which part or parts of the framework apply” (p.300).

In this indexing stage, I went through each transcript, highlighting each meaningful passage of text and selecting and attaching an appropriate code from the thematic framework. This phase also involved defining and refining the thematic framework, after the initial application across the data set. Furthermore, the researcher reads the groups of indexed data to evaluate the coherence of the data extracts. The sections of the data that have not been indexed will be examined in order to establish if any important themes are missing from the framework (Spencer et al., 2013a).

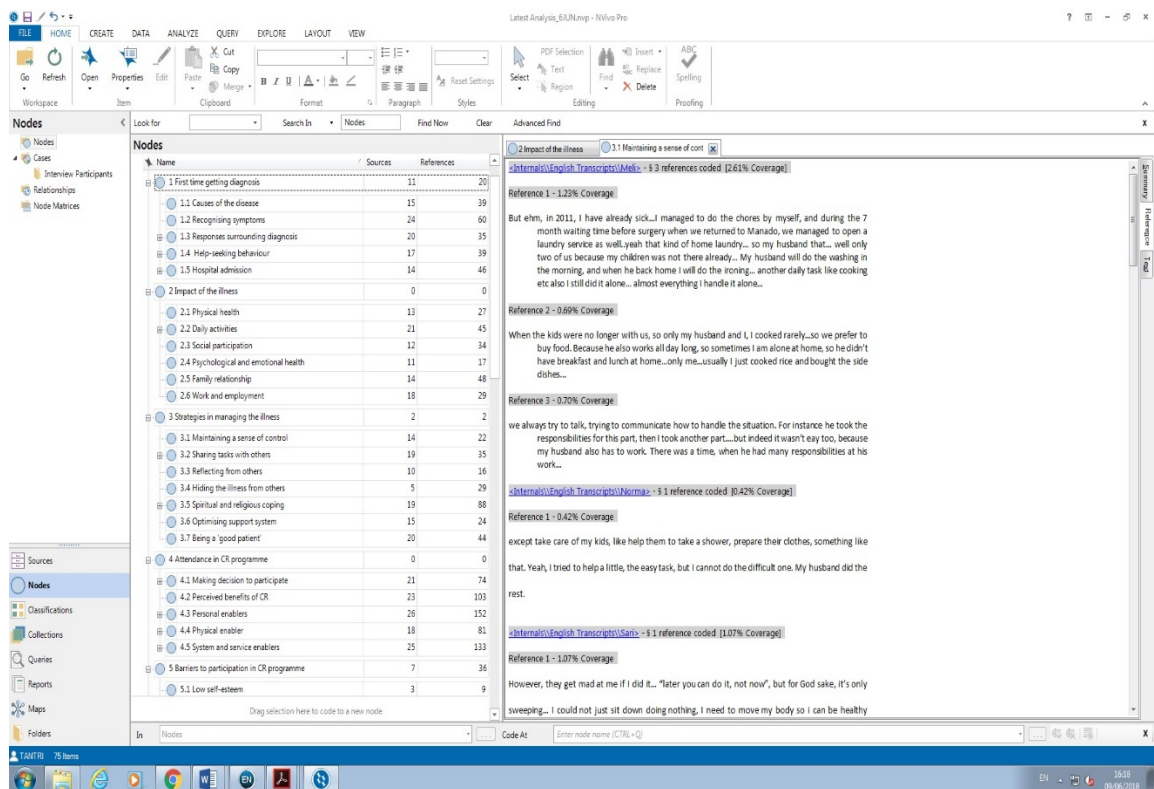


Figure 3.3.4 Example of indexing process in NVivo

3.6.5 Charting data into the framework matrix

According to Spencer and Ritchie (1994), the purpose of the charting stage is to organise the data into a more manageable format in order to facilitate the process of data interpretation. This phase involved summarising the indexed data for each category and organising the summaries into chart form.

Once all the data had been coded using the framework, the final steps undertaken were generating a matrix and charting the data into the matrix. In this stage, the data that has been indexed in the previous stage was arranged into thematic matrices. This means that the data was lifted from its original text and placed into charts. Each theme has its own matrix in which each sub-theme is allocated a column. The list of themes and subthemes in the initial thematic framework became a horizontal set of column headings in the matrices. The first column of a matrix was reserved for case identification in which demographic information such as age, education, employment, and marital status was entered. Each case was then assigned a particular row and will remain in this same location on every matrix, so that both cross-case and within-case comparisons can be made.

At this stage of the data analysis, I worked through each framework category by summarising all the data that have been indexed in that category, and in addition included quotes from participants. I made a summary for each category and each participant. I found the use of CAQDAS was very helpful at this stage because NVivo provides the feature where I could link the summary to the relevant part of the interview transcript. In short, when I clicked on the summary, it would retrieve the transcript text linked to that part of the summary. This facility made it much easier for the researcher to move between the summaries and the original transcribed text than if that software option had not been available (Swallow et al., 2011). Although NVivo also has the feature to generate matrices automatically, I still reviewed the summarised data in each cell manually to ensure that it included enough detail and context and retained the original meanings, without losing 'the voice' of the participant. Using the CAQDAS also gave me the confidence to write shorter summaries, because the original data on which the summary was based can be accessed with a single mouse click.

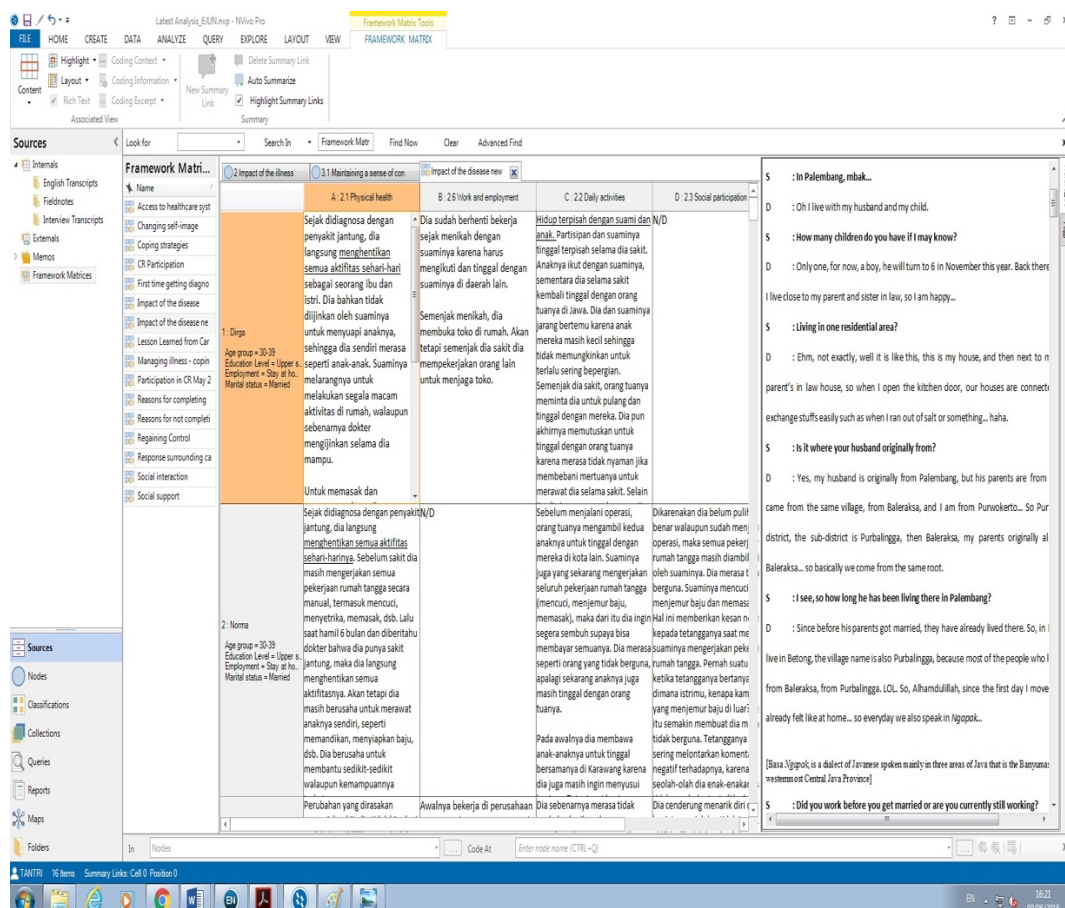


Figure 3.3.5 Sample of framework matrix

3.6.6 Mapping and interpreting the data

Before moving on to the next stage of the analysis process, I took a step back to identify the key questions that needed to be asked of the data in order to meet the research objectives and in accordance with the study's framework. In this way, the research process was both structured and iterative, moving from micro to macro data. The iterative process ensured that the overall context of the data was not lost in fragmentation, and also that all of the data was finely examined. I found this phase to be the most challenging process during data analysis. Ritchie and Spencer (1994) acknowledged this issue, pointing to how the researcher should employ their intuition and imagination in interpreting meanings, rather than simply examining the data mechanically. Taylor (1971) as cited in Peshkin (2000) pondered:

"But how does one know that [an] interpretation is correct? Presumably because...what is strange, mystifying, puzzling, contradictory is no longer so." (p.5)

The stage of mapping and interpretation involves the process of analysing the similarities and differences of the key characteristics, as laid out in the framework matrix. To interpret the data, I followed the steps that have been outlined by Ritchie et al. (2014) for the process of abstraction and interpretation. The process began with descriptions and involved developing categories and identifying linkages between the two processes. I tried to understand 'what is happening' within a theme or sub-theme that was located within a set of data summaries in the framework matrix (Ritchie et al., 2014). During this stage, I tried to go beyond descriptions of individual cases towards the developing of themes. When interpreting the data, I was also attentive to the perspective of intersectionality as described in section 3.4.1. Hence, I considered how different social categories affected women's experiences with heart disease and their participation in CR programme. As I outlined in section 3.4.1, during this stage I was constantly asking question: *"How gender interacts with other social categories? Which dimensions of the experience are interacting with gender?"* (Bilge, 2009, p. 7)

Furthermore, there were times when I found it easier to work outside of NVivo, when I used the spreadsheet option to work on the interpretation of the data. I input the framework matrices to Microsoft Excel because the data was then easier to handle. I

read through a few data summaries relating to a theme or subtheme that were produced using the framework to map and interpret the identified differences and similarities. Then I listed the elements that characterise and differentiate the responses. Once elements had been identified, I sorted the elements that fitted together according to the underlying dimensions. Following that, I examined the data again, combined elements into different types of responses in order to produce a set of categories that is able to discriminate different manifestations of the data. Each emerged category was given a label reflecting its contents. The initial categories were fairly descriptive and stayed close to the data (Ritchie et al., 2014). In the next stage, I constructed higher-order, more abstract classes, to which lower-order categories were assigned, so achieving a greater level of integration within the data. Throughout the process of data analysis, I had a regular discussions and meetings with my supervisors to maintain the believability of the research process and findings.

3.7 Ethical issues and considerations

Some of the ethical issues, such as gaining access and obtaining consent are discussed in section 3.5.2. This section outlines how I have approached some of the key areas of ethical concerns in this research.

3.7.1 Possible benefits and harms of the study

One important aspect of the ethical considerations in conducting a study involving human subjects concerns balancing its benefits and risks (Beauchamp and Childress, 2013). Although there was no intention to cause harm to others in this study, the researcher still needs to assess any potential risks associated with this information gathering research process.

In this study, one of the central aspects of concern was related to the interviews with women. Rubin and Rubin (2012) suggest that one essential component of the researcher's ethical responsibility towards the interviewee, is ensuring they do not cause any harm. Rubin and Rubin (2012) stated,

"Your interviewees should be no worse off, and ideally should be better off, for having taken the time to talk with you." (p. 89)

The possibility existed that the women would become distressed during their one-to-one in-depth interviews, as they had to share the unpleasant experience of struggling with the consequences of a life-threatening illness, as well as recovering from the illness. Such memories and experiences could induce psychological stress and discomfort for the participants. Therefore, the women patients were potentially vulnerable when entering the research process. These interviews could, and in one objective sense were designed to, invade women's privacy as they were to reveal their inner thoughts, attitudes, and behaviour about both illness and recovery; such a focus might not be easy for some of the women to deal with (Crandall et al., 2006). In addition, women may not be willing to open up and provide sufficient information, particularly on sensitive personal issues. I was aware of these concerns and I made the women aware that there was a risk of personal upset when discussing the painful experience. This could be emotional to some of them, and possibly even the female researcher. Therefore, I demonstrated significant empathy and good communication skills that depicted an eagerness to listen to their stories. In addition, I informed the women about the option of answering a question or not. This approach ensures that participants do not feel forced or under pressure to answer any questions that made them feel uncomfortable. I explained this potential risk in the participant information sheets. In addition, I also included a section in the study protocol, outlining what the researcher would do if someone became distressed, such as directing participants to support services that were available in the hospital where they were being treated.

According to Beauchamp and Childress (2013), the principle of beneficence means "to act for the benefits of others" (p. 203). Gelling (1999) argues that it is unethical to involve people in the research if there is no expected benefit to others. More importantly, potential benefits should exceed potential risk in research (Holloway and Wheeler, 2010).

It is arguable there were certain benefits for the women who participated in this study. Rubin and Rubin (2012) suggested that having the opportunity to discuss experiences in an interview could be beneficial to the participants. Some women appreciated the opportunity to talk about their experiences of struggling and living with heart disease. The study gave the women the opportunity to share their stories and to have their opinions and views attentively and fully listened to; perhaps for some an unusual experience. One of the advantages of having the same gender, and sharing similar

cultural values with the research participants, is that I represented someone with the capacity to empathically listen, understand, and show real concern. Indeed, some of the women that I interviewed expressed that they enjoyed having the chance to discuss their experiences with me and thanked me for the opportunity. Some women approached me personally several days after the interview stated that they found the interview session with me was enjoyable and said that they would be happy to have more sessions with me. They felt that they could share their darkest feelings without being judged. On a broader perspective, I am hopeful that the findings of this research will contribute to providing useful information into the role that CR plays in the recovery process of women with heart disease. The findings of this study may contribute to the development of a targeted intervention strategy for women's cardiac rehabilitation, ensuring a more effective use of resources to optimise CR programme attendance. Such an initiative should be designed so that it can proactively address and meet women's recovery needs in the future.

3.7.2 Confidentiality and anonymity

To ensure confidentiality of the data for the participating women, I kept all information securely and created backup files as well. I only shared data extracts publicly once all identifiable information about individuals had been removed. With regard to confidentiality, no information obtained during the study was discussed or shared with anyone outside of the research team, without written permission from the participants. Moreover, to protect the anonymity of the participants, I used pseudonyms instead of names on the interview data. I kept all written data in a locked filing cabinet while I kept electronic data in files protected with passwords, with only the research team having access. These data will be destroyed in due course, as specified by committee protocol of the University of Edinburgh and COMREC. All information in hard copy will be shredded, while electronic copies will be erased from all electronic devices. I assured the women that all the information I gathered from them will be kept secret, and that they have the right to decline to answer any questions that made them feel uncomfortable.

I made every effort to maintain confidentiality and data security procedures that helped protect a participant's identity during the data collection and analysis research stages. I kept all information about study under my strict custodianship; only

pseudonyms were used in the transcripts of interviews. Also I assured the women that their identities would not be revealed in publications arising from this study.

3.8 Trustworthiness

According to Gerrish and Lacey (2010) there are two primary concepts required to ensure the rigour of any research: validity and reliability. However, the terms validity and reliability are not applicable within the nature of qualitative data analysis. The most often quoted concept of establishing validity and reliability in qualitative research is the notion of trustworthiness; a concept that was developed by Lincoln and Guba in their seminal book *Naturalistic Enquiry* (Lincoln and Guba, 1985).

In this section, I address each of the trustworthiness criteria as suggested by Lincoln and Guba (1985), including: i) credibility, ii) transferability, iii) dependability, and iv) confirmability.

3.8.1 Credibility

According to Creswell (2013), credibility refers to the credibility of the data, or believability of the findings, from the perspective of the participants in the study. This study utilised three strategies to increase its credibility. First, I allocated six months for a) recruiting participants and b) data collection at the research site; considered this a process of prolonged engagement which was vitally important to produce credible findings (Lincoln and Guba, 1985). This process allowed the researcher to build trust and rapport with participants over time, in the CR site. Polit and Beck (2013) asserted that building rapport and trust with the participants through prolonged engagement will increase the likelihood of obtaining rich and useful information from them. By following and attending the activities in the CR unit on a daily basis, the patients became familiar with my presence, so were not particularly surprised if I invited them to participate in the research.

Secondly, I adopted member checking as one of the strategies to ensure the study's credibility. Lincoln and Guba (1985, p. 314) defined member checking as

“...the process whereby data, analytic categories, interpretations, and conclusions are tested with members of those stake holding groups from whom the data were originally collected...”

As suggested by Lincoln and Guba (1985), member checking can be done either formally or informally and is a continuous process. In this study, I carried out informal member checking during interviews with participants, through deliberate probing and summarising or repeating information back to participants. This method helped to ensure that I understood what participants were telling me. Lastly, I also used peer debriefing to establish credibility. The purpose of peer debriefing is to inform the researcher of the status of his or her posture and process as well as to ensure the collection of valid information (Lincoln and Guba, 1985). Peer debriefing was done with my research supervisors in the UK throughout the research. This debriefing procedure provided me with an objective view of the quality and content of the data collected. I also shared the data transcripts with my supervisors.

3.8.2 Transferability

Transferability is concerned with the extent to which the findings of qualitative research can be applied in other situations or settings (Lincoln and Guba, 1985). Guba and Lincoln (1989) suggested thick description as the main technique to achieve this outcome. Therefore, to ensure the transferability of this study, I provided extensive detail about the research setting, methods, participants, and the assumptions that are central to this study, so as to enhance its transferability. This strategy should allow the reader to form their own judgements whether the findings may be applied to another setting or group of people experiencing a similar phenomenon.

3.8.3 Dependability

Dependability is related to the stability or consistency of data over time (Guba and Lincoln, 1989). To enhance dependability, the researcher has to be transparent about a) the research steps taken; b) any decisions made from the start of a research project and c) the development and reporting of findings (Topping, 2010). The strategy adopted to enhance the dependability and confirmability of this research was through an audit trail. An audit trail involves careful documentation of all aspects of the inquiry; the auditor, who is the external examiner, will carefully check “the decisions, analytical processes, and methodological decisions of the primary researcher” (Parahoo, 2006, p.410). The use of NVivo 11 to store and manage the data was also aimed to enhance dependability.

3.8.4 Confirmability

Confirmability refers to the degree of neutrality and accuracy of the data or, more often, to what extent could the findings be confirmed by others (Lincoln and Guba, 1985). To enhance confirmability, the procedure for checking and rechecking the data throughout the study was documented. My thesis supervisors were the auditors. Throughout the analysis process, interpretations were constantly shared and discussed between the researcher and her thesis supervisors, in order to challenge the identified themes and their connections in the form of peer debriefings (Lincoln and Guba, 1985).

3.9 Chapter Summary

A detailed discussion of the research design and methods for this PhD research has been presented in this chapter, as have the ontological and epistemological positions underpinning this research. I set out my argument regarding how feminist qualitative research fitted with the research aim and questions, as well as an examination of my position during the study. Following this, I outlined the research method employed; research settings, participants' recruitment, data collection, and data analysis were presented. In the last section, ethical considerations pertinent to the issues of the research and trustworthiness were discussed.

CHAPTER 4: Findings 1

Women's experiences of living with heart disease

4.1 Introduction

The focus of my study is to investigate women's participation in a phase two CR programme in Indonesia. During the data analysis, it was apparent that women's participation in the CR programme was strongly influenced by their experiences of living with heart disease. Therefore, during the data analysis, I extended my focus to explore the consequences of heart disease on women's day-to-day lives. In this chapter, I present findings that address the question of how gender shapes women's experience living with heart disease. Specifically, the focus is on a) the impact of those heart problems on women's everyday lives and b) the strategies the women employ to manage their heart disease. I believe that understanding women's experiences of heart disease would be a crucial aspect of gaining an understanding of women's attendance, or non-attendance in their CR programme.

In this chapter, two major themes emerge from the participants' stories: i) a threat to gender identity, and ii) saving face in front of family and others. In the first section I analyse and discuss how heart disease affects women's sense of self as well as to fill their day-to-day roles as mothers, wives, workers and household managers, amongst others. Second, under the theme of saving face in front of family and others, I present the findings related to women's strategies in managing the disruptions imposed by the disease on their day-to-day lives. To maintain the believability of the findings, I provide quotes from the participants as the primary source of data in this chapter. Pseudonyms has been assigned to each participant to maintain confidentiality and their anonymity.

4.2 Threat to gender identity: *'I feel useless!'*

Participants' narratives about their illness linked experiences, including the causes of heart disease, its impact on their day-to-day lives, as well as the severity of the

disease, are all strongly influenced by their cultural values and traditions that framed their health beliefs and behaviour towards heart disease. Hence, complex interplays between cultural values/ethnic affiliation, religion, and age produce participants' gender position and help them to articulate the impact of CVD on their day-to-day lives as a woman within Indonesian society. The participants clearly felt a threat on their identity as a woman following the diagnosis of CVD.

In their understanding of the factors that trigger and aggravate heart disease, participants' stories indicate a number of similarities. First, for the participants who suffered from coronary heart disease, they agreed that their diets and lifestyles were the major causes of the heart attack. Second, participants who had congenital heart disease attributed hereditary (genetic) factors as the underlying cause of their illness. Third, some women expressed that they do not know what factors had precipitated their cardiac event, by referring to their recent emergency as a "sudden experience". Lastly, some respondents believed that emotional distress was the primary cause of their heart disease. Based on their stories, emotional distress was most commonly caused by "thinking too hard" or from what the participants described as stress. Day-to-day stressors, such as financial issues, job, or physical exhaustion were mentioned by the participants as factors that had contributed to the development of their disease. Focus in the issue of being stressed is the result of Indonesian women being seen as responsible for a range of social duties. These duties include i) managing domestic tasks, ii) managing the money in the family, iii) making sure that there is enough money to provide the needs of the family, iv) taking care of children v) taking care of her husband, and vi) many other family matters.

In describing the impact of heart disease on their day-to-day life, each woman in this current study used their valued life experience prior to the cardiac event as the main comparison standard. Although the details of each life story differed based on the woman's social and material conditions, major thematic similarities were apparent. In their narrative, the women mostly described their life histories in terms of their roles as a mother and/or a wife and how heart disease interrupted and altered their ability to perform these roles. Their lives were organised around the needs of others, and in some cases, the additional demands presented by paid employment.

From the narratives of the participants, it was evident that their roles as a wife and a mother have been central to their identity as a woman. The women in this study described that “everything has changed” since experiencing heart disease. Many women portrayed themselves as self-reliant, socially and physically active, and who previously had occupied a central role in the family as the key caregivers instead of, as now, care receivers. They saw themselves as having been prominent actors in the lives of others. Therefore, due to her illness each woman, who had previously occupied a vital role within a family or society, lost her status. As the women were no longer able to perform their normal functions and roles, due to their illness, that perceived demotion posed a threat to their identity. Manurung described her feelings:

“How do I describe my feelings; I feel troubled because I can’t do the housework. How to do it? My son helped to sweep the floor, but you know, ‘a man is a man’, right? Indeed, he swept the floor, but ‘just like that’. So yeah, it troubled me a lot, because I cannot handle it on my own”. (Manurung, Batak, 66)

There was dissatisfaction in Manurung’s tone when stated *‘just like that’* referring to how her son had helped her with the cleaning task; clearly he had not met his mother’s high standards. As outlined in section 2.6.3, based on the cultural expectations and social norms in Indonesia, women are expected to fulfil gendered expectations, including dedicating their lives to the well-being of the family as well as doing household chores; not to mention performing the roles of a wife. In addition to that, women are also expected to contribute to community development and to fulfil social obligations at the socio-cultural level (Niehof, 1998). Therefore, when they found themselves unable to work and take on active roles in the family, it caused the women to feel less useful to the family; a negative situation which they perceived as a threat to their identity as a woman. This condition is also combined with a growing awareness of their inability to manage current daily activities. The changes in their physical and emotional dispositions lead the participants to perceive that they were no longer the same person as they had been. One participant, who had to send her children away to live with her parents in law since her symptoms deteriorated, stated:

“I feel like a useless person, you know... He [husband] did the laundry, hung the washing, prepared the meals... hm, it gave the wrong

impression when my neighbour saw him hanging up the washings outside. Once my neighbours asked "Where is your wife? Why does she not hang up the washing?" That made me feel like a useless person...moreover my daughter was with my parent in law too. Yeah, so I became a subject of gossip in my neighbourhood. They said, "uh it must be really good to be you, you can relax." Yeah, maybe because my kids were with my parent in law, so they thought I had nothing to do at home. I feel like useless". (Norma, Javanese, 30 years old)

Likewise, Raline made similar comments:

"I feel uncomfortable of course, as in the past, I used to do many activities, and now I do nothing. The feeling is hard to describe, but I still want to try. Like some time ago I asked my sister, "Tin, let me try to sweep the floor." Then I swept the floor, only a bit, but I felt that my hand wasn't strong enough. I wanted to try, but I was too weak. Yeah, so uncomfortable. Usually, I did many activities, now nothing, so uncomfortable". (Raline, Betawi, 32)

These findings indicate how the participants struggled with disappointment when they did not have sufficient energy to perform the usual household activities. They expressed a sense of frustration, or in their words *'the feeling that is hard to describe'*, about being unable to accomplish their traditionally assigned roles as a mother and a wife. Scholars have remarked that women have a central position in an Indonesian household. In a classic study on Javanese women's roles and positions, Geertz (1989, p. 46) suggested that within the domestic domain, the wife has the power to make most of the decisions and to manage the finances of the household. Moreover, heart disease not only interrupted the participants' ability to perform their domestic tasks, but some participants also described how their heart disease had affected their appearance and self-image, particularly related to the fluid retention in the stomach. As Meli described:

"I was so stressed, feeling exhausted, not only physically, but mentally. Because firstly, it was not only because my heart condition, but also my stomach appearance. Everywhere I go, people gave me that weird

look and often asked me when I am going to give birth. So, it became a burden to me as well...” (Meli, Minahasan, 36)

Despite diverse backgrounds of age, socioeconomics and ethnicity, to some extent the women in this study shared similar values regarding their roles as the primary caretakers for the family. For those reasons, women in this study who previously occupied a central role within their family, found it particularly difficult to lose their former position and to have to depend on others to perform their normal duties. The inability to perform their central roles in the family contradicts the ideal womanhood/motherhood identity and obligations prescribed and generally endorsed by the Indonesian sociocultural system. Under this theme, three sub-themes emerged: i) losing control over everyday life, ii) burdening others, and iii) it's a test from God.

4.2.1 Losing control over everyday life: ‘I feel like I have no freedom!’

Despite their diverse backgrounds, all the participants in this study identified a lack of autonomy and control as the most significant impact of the physical impairment and functional limitations associated with the disease. Many women in this study described how they had lived with symptoms for long periods, particularly due to the waiting times for surgery; with the majority of the participants having to wait for more than six months. During the interviews, the participants spoke of how the illness caused disruptions in many aspects of their lives. Heart disease had a significant impact on their ability to carry out their normal role functions as a mother, a wife, and a member of society. The women reported a sense of ‘not being in control of their bodies and daily activities’, as well as out of control within the home due to their inability to maintain normal domestic standards.

4.2.1.1 Physical and functional limitations

The participants described a loss of control over their bodies caused by breathlessness, fatigue and decreased mobility; the physical realities that hindered their daily lives as well as being a source of frustration. When answering the question on what has been changed following the cardiac event, one participant described:

“There has been a significant change. Before I had the heart attack, I could walk as far as I liked, I could do high-intensity exercise without feeling tired or experiencing shortness of breath. I was shocked being told by the doctor that I had three 100% blockages in my heart since I did not feel any sign of heart attack before”. (Hana, Sundanese, 36)

Physical limitations led to the changes in women’s social roles, both within the family and within their community. With regard to social participation, one of the participants, Meli, used to be an activist and participated in various volunteering activities prior to her diagnosis. She and her husband moved to Papua in 2009 to do volunteer work. Initially, they planned to stay permanently in Papua. However, after giving birth to her second baby in 2011, her health condition began to deteriorate. As a result, they decided to move back to their hometown (in a different island) to seek better medical care. She described her frustration with going through this life transition:

“What I felt at first... because I used to be a person who loved to do everything such as sport, the activity that I enjoyed the most in the past. Then I always go everywhere and do everything by myself, although I have a husband, I prefer to do it myself. For example, when I needed to replace lamp or something else, I did it by myself. But when it started to relapse in 2011, it was hard. I couldn’t do anything like before. Even just to walk from here to there [the patient pointing the distance from the seat to the door, approximately 1.5 meters], was already a struggle. So after that, I was totally dependent on my husband. Everything has changed since then”. (Meli, Minahasan, 36)

Likewise, Ningsih explained the impact of the illness on her roles in the family:

“Oh, the change since I have this illness was not being able to do activities, which would be too tiring, or too much, so I can only do a little cooking for my husband. I can no longer wipe the floor, or wash laundry by hand. I am no longer strong enough for it. I used to be able to handle it, before I had this illness [...] I actually feel bad for my husband because it is my duty that he is taking over. I just feel bad...

It is something like, well, a feeling of pity for him, isn't it? I am feeling sorry for my husband". (Ningsih, Javanese, 33)

These findings illustrate how the physical effects of their heart disease caused a significant change in women's capacity to perform 'normal' duties and valued activities in their everyday lives. This finding concurs with several other studies from both a western (Pihl et al., 2011) and Asian perspective (Seah et al., 2016). These studies reported that the symptoms of heart disease often created various restrictions on many aspects of the individuals' lives, mainly because of reduced physical ability. Being unable to fulfil their previous social roles, as wives or mothers, caused them to experience psychological discomfort. Statements like, *"I feel restricted"*, *"I feel uncomfortable"*, or *"I feel useless"* were very common across participants' narratives, as they recounted their experiences living with CVD. Many participants expressed similar concerns about the illness that had caused them to lose their normal lives, resulting in specific emotions accompanying this loss. This outcome is consistent with the assertion from Anderson (1992, p. 217) who argued that having a chronic condition is an "assault upon many areas of everyday life, influencing the many aspects of an individual's and family's life, autonomy, and independence".

4.2.1.2 Separation with children

Most women with young children in this study (8 out of 12 women) had to live separately from their children, due to their degenerating physical condition that required them to focus on their treatment. They asked their parents or relatives to look after their children during their treatment period. One participant described her experience:

"I was separated from them when the small one was only eight months, so, I couldn't breastfeed her anymore, right? Thus, it has been around a year I haven't seen my daughter again. Since she was only eight months, she has been taken care of by my parent-in-law..." (Norma, Javanese, 31)

Another participant, Meli, who has two daughters aged six and four and a half years, had to leave her daughters with her father and her sister. Since her condition got worse to the point that she could not do anything since October 2015, she decided to

get the cardiac surgery. She was very sad not only because she was separated from her daughters, but also because her daughters had to live separately from each other. She said:

"I haven't seen them for almost a year [...] They lived separately, maybe around 45 minutes by motorcycle or car. So, they haven't met each other often too. Because they also went to a different school, one in primary school, the small one in kindergarten. Different...they also lived in a different place." (Meli, Minahasan, 36)

Leaving their children under the supervision of others was a difficult decision for the participants; at the same time, they felt that they had no other choice. For the participants, the role of caregiver for children was most important, thus for the young women with relatively young children, they found it very hard to accept their diagnosis and condition. For this reason, participants also expressed feelings of guilt about not being able to look after their children properly, since they could not fulfil their roles as a good mother. Dirga explained:

"I felt like I did not give much attention to my son. I never took him to shopping mall, yeah like that... uh, it is so sad." (Dirga, Javanese, 31)

Dirga was a woman in her early 30s; she discovered that she had a heart valve disorder in 2015. Since she was diagnosed with heart disease, she moved back to live with her parents and lived separately from her husband and son. She described her frustration to live far away from her own family:

"Yeah in term of my roles in the family, now I still feel... You know, I still cannot do my roles like before, yeah because I moved back to live with my parents, so the distance [...] I feel like I couldn't fulfil my responsibilities as a good mother and wife. Because I live far away from my family, so I cannot take care of my kid, my husband, yeah I am not able to do that." (Dirga, Javanese, 30)

The changes in household roles, responsibilities, relationships, and routines arise from a combination of the effects the person's condition has on their capacities,

needs, and perceptions. The restrictions on their ability to perform their former roles could undermine or threaten a woman's identity. On top of that, her inability to provide support to family and friends also can lead to erosion of self-worth (Dalal and Biswas, 2009).

The women stated they felt less useful when they were unable to look after other family members. The findings clearly indicate that the failure to perform the expected roles as a good mother/wife, based on the prevailing standards in Indonesian society, decreases the participants' self-esteem and leads to a sense of 'being useless'. The feeling of being useless is not just because of their inability to perform their former roles, but also as a result of perceived failure or violation of standards and norms in the community.

4.2.1.3 Being watched

The women frequently described that the lessened freedom and independence were not a mere consequence of their illness, but also come from their families that tended to be overprotective. Sari who lived with her husband and her teenage daughter described her frustration when her husband told her to stop her usual task of cleaning the house when she thought still able to manage it. She explained,

"They get mad at me if I did it... "Later you can do it, but not now", for God sake, it was only sweeping the floor... I could not just sit down all day doing nothing [...] I think it's okay as long as I don't lift heavy stuff..." (Sari, South Sumatra, 44 years old)

Similarly, Dirga made the following comments:

"I was not allowed to feed my son; he was with my husband, right? So, I felt like a child myself at that time, just ate, slept, ate, slept... that's all. My husband did not allow me to do any daily activities, although my doctor said that it was fine as long as I could handle it, but my husband didn't allow me to do anything." (Dirga, Javanese, 30 years old)

From their narratives, it appears that some of the women complained that their family were overprotective and more worried about their conditions than the patients were.

They felt that they had lesser autonomy and freedom in performing their roles because their family kept their eyes on them. When one of the participants stated that she felt like a child herself, it was apparent that heart disease and the restrictions from her family had threatened her sense of self. These feelings were more apparent and frequent among those who were still relatively young women or who had young children. This finding resonates with other studies, which reported overprotection by significant others (Vosbergen et al., 2013, Condon and McCarthy, 2006). White et al. (2007) in their study of women's experience of MI in the UK also reported that women expressed feelings of anger and frustration due to their family's overprotective behaviour. However, Dumit et al. (2015) reported that the majority of the Lebanese cardiac patients did not seem bothered by their children's tendency to be overprotective. The reason for this is that the majority of the participants were in the older age group. Therefore, the family caregivers feel obliged to take care of the parents as part of performing their cultural roles, while the parents considered their children to be caring and were thankful to them.

4.2.1.4 Marital conflicts

Although the majority of the participants described that they received a great deal of support from their spouse, children, or extended family members, some participants revealed information suggesting disrupted relationships, such as marital conflict, or communication issue with family members. For example, Titi explained that since being diagnosed with congenital heart disease, she experienced conflicts with her (now ex) husband. She described that her husband cheated on her and married another woman upon learning that she had heart disease. Her husband could not accept her condition, particularly since Titi's doctor had advised her not to have any more children. She stated:

"I knew that I had heart disease in 2007 when I saw a doctor here. Then I went home and told my husband about it. I told him that with my illness, I could not have any more children because it would be too risky, at that time our son was five years old [...] in 2008, he cheated on me, and then he married again with another woman. From 2008 to 2014, he just didn't care when my illness relapsed many times. He said I just dramatized the situation. So yeah, finally I asked for a divorce."
(Titi, Javanese, 36)

These findings highlight the definition of womanhood in Indonesian society, which considers motherhood as a defining characteristic of adult womanhood. Thus, the failure to conceive may mean that women are divorced, abandoned, or willing to be in a polygamous relationship. The issue of polygamy is still a source of debate in Indonesia. In several countries including Indonesia, the practice of polygamy is not openly banned, rather it is stringently regulated through very strict rules (Mutaqin, 2018). Polygamy remains because the prohibition of this practice would be in direct conflict with the Quranic verse that states, *“And if you fear that you will not deal justly with the orphan girls, then marry those that please you of [other] women, two or three or four. But if you fear that you will not be just, then [marry only] one or those your right hand possesses. That is more suitable that you may not incline [to injustice].”* (Al-Qur’an IV:3).

4.2.1.5 Withdraw from social participation

Some participants in this study described that when their symptoms deteriorated they had to withdraw from participating in social activities. Ori, a middle-aged woman, used to be a *qasida*’s (*Islamic musical group*) lead singer in her village before her symptoms deteriorated. She joined the *qasida* group not only as a hobby but also because she earned money so she could help her family’s finances. She described that she was one of the persons who initiated the musical group until they gained popularity in their village so that they received more invitations to perform in the neighbouring villages. With her new roles, she claimed that her husband always supported her and never prohibited her to do the activities that she enjoyed. However, due to her recent cardiac event and the subsequent treatment that she needs to attend, the group had to replace her with someone else. She explained:

“Now they are replacing me, with someone else because I wasn’t able to perform, if I still able to perform they wouldn’t replace me. [...] It feels weird you know, because of my illness, well, maybe Allah tested me so I would have to rest and I wouldn’t be too exhausted.” (Ori, Sundanese, 36)

Her comment indicates profound displacement in one important aspect of her social world. Therefore, she described that one of her goals, after she has fully recovered,

was to be able to join the group again in addition to her primary roles at home as a wife and mother. Another participant described that she was actively involved in several organisations. However, she was no longer able to remain involved, particularly after she got married and was then diagnosed with CVD. She explained:

“I used to be an activist. I participated in many social activities. Usually after I finished work, before I got married, I attended meetings with my juniors in the college before I was actively involved in the religious activities there. So, I went there quite often. [...] It has been changed after I suffered from heart disease. If I want to do an activity outside, I should be with my husband. I had to wait him from work so he could take me out at night.” (Meli, Minahasan, 36)

Meli's account illustrates that it was a combination between marriage and heart disease that hindered women's participation in social activities. Ningsih described a similar story,

“I withdraw from social activities indeed; I don't do many activities outside. Sometimes my neighbour invited me to join the religious gathering every Friday night, or on Sunday usually we have Quran recitation in the mosque. They invited me, but I don't really...well, I don't tell them about my condition. The problem is, if I do many activities outside, I would not have energy left to take care of my husband at home.” (Ningsih, Javanese, 33)

However, one participant who worked outside the house prior to the cardiac incident described that she had a way to stay in touch with the social activities in her community. She asked her neighbour to keep her informed by texting her on what is going on. She continued using this method even after her cardiac event. Thus, she said she did not feel left out.

4.2.1.6 Giving up job/employment

Based on the participant's narratives, the women participated in this study can be categorised into four different groups: 1) working women who have a professional or formal job outside the home, 2) housewives, 3) retired women, and 4) women who

used to be financially independent by working outside the house, but voluntarily gave their job up due to their illness. The participants expressed concern about giving up their work because of their illness. One participant, Hana, used to work in customer service in the food company, Nestle. Following the heart attack in 2015, she took a three-month sick leave. She still returned to her former job, but she then found out that her symptoms deteriorated due to physical exhaustion. She described her situation:

“Sometimes I felt good, no complaint for several months, but when I was not in good condition, I feel like burdening others. Let alone that I am still in the productive age, which in normal condition I should be able to help my parents, or whatever. In contrary, they have to take care of me.” (Hana, Sundanese, 36)

Raline had been selling vegetables in a traditional market in Jakarta for 6 years, and she felt frustrated when she had to give up her job a year earlier because of her heart disease. Although Raline lived with her son and her father, she was the primary earner in the family because her father was already retired, and her son just finished high school and did not have a permanent job yet. Therefore, she had to work hard to support her family economy since her mother passed away in 2010. Raline’s husband left her and her son a few years back. Besides her role as a primary earner in the family, Raline was still the caregiver for her father and responsible for all the housework chores. This situation made her felt uncomfortable, in which she explained,

“Sometimes I feel, oh God, when I am being ill like this, I cannot take care of my father. The food, my father a bit picky about food, he doesn’t want to eat the food from someone else, I mean he only want to eat the food that I prepare. Sometimes, I feel pity for him. Now my sister’s in law prepares his food but he also doesn’t want to eat it.”

After a short pause, Raline continue:

“I feel like a helpless person. Without help from the other people, I cannot do anything. Yeah, I feel so helpless.” (Raline, Betawi, 32)

Raline's account illustrates how she had to struggle in maintaining family harmony, while simultaneously she had to struggle with her own condition. She experienced a conflict between providing care for others (particularly her father) and providing care for herself in day-to-day life. She felt guilty about not doing enough for her father even though she was in a condition that required care. This situation concurs with the findings of a meta-analysis conducted by Galick et al. (2015) which identified caring for others in the family as an important part of women's identity.

A significant role change from a household manager, responsible for controlling the household and financial affairs, to a person who considers herself to be weak, has caused emotional distress for most women in this study. They felt that they had lost their previous social position in the family. Taking away the functions that symbolised independence and autonomy prompts the women to realise that life is becoming increasingly restricted for them. For this reason, the women experienced a gradual loss of their valued independence and became more aware that they cannot do, and are not allowed to do, the things they had valued and enjoyed in the past. This situation seems to bring about feelings of resentment and concern focused on, and caused by, their inability to act in the roles that they had before. The sense of inadequacy, therefore, can lead to a devaluation of the person's worth in the minds of that person and others (Bedford and Hwang, 2003). These findings are consistent with assertions by Rodríguez-Prat et al. (2016) who argue that the loss of functionality undermines a person's sense of dignity. Manurung's narrative best illustrates this tension:

"It is so depressing. I feel like I have no freedom, as I cannot do anything as before. My son told me, "It's okay ma, just leave it like this. When you recover, you can handle it again. Now you just need to focus on your health." So at home, when I move a little bit, they would ask me, "Where are you going? What do you need? If you need anything just tell me". (Manurung, Batak, 66)

Likewise, one retirement-aged woman in the study, who lives with her three adult sons and two daughters-in-law, expressed similar comments,

"I enjoy my grandchildren, but I can no longer take care of them. It is just so depressing for me." (Dju, Betawi, 62)

The inability of the CVD patient to adequately perform normal role functions, based on the Indonesian standard of women's roles, seems to affect their sense of self-worth as well as sparking off remorse. The findings are similar to previous qualitative studies among women who have fibromyalgia in Spain (Briones-Vozmediano et al., 2016). Their findings revealed that being able to perform household chores was important to the women's sense of identity and self-esteem. Similarly, studies among male with sudden cardiac arrest also found the men in their study concerned about their ability to carry out their former roles and responsibilities in the future, such as their ability to lift heavy objects, to play sports, or to exercise vigorously (Uren and Galdas, 2015, Simmonds et al., 2013). Losing the functions that frequently used to symbolise masculinity for men has profoundly affected their sense of self-worth, emotional/social wellbeing, and mental health. These findings confirm the traditional sexual division of labour, which embedded the male as 'breadwinner' and female as 'housekeeper'.

It was clear that the women in this study struggled with various issues in their everyday lives, including marital relationships and financial struggles. Loss of control over everyday life issues has undermined or threatened the women's sense of self. They became very concerned about losing standing in front of the others, as the result of a perceived failure to meet society's expectations regarding their role or status. The narrative of the participant below portrays an Indonesian woman's perception of the ideal image of a good woman that cannot be separated from their roles as mothers, wives, and caring for others:

"although we have everything, if we don't have kids, if we don't have a husband, we are useless... You know it's just empty. Although we are happy, but we don't have kids, we don't have a husband, although we are healthy, but we are useless. Yes, we are just useless. The only thing that makes us useful in life... em yea by having kids, by having a husband that makes our live more peaceful." (Lastri, South Sumatra, 55)

From Lastri's account, it became quite apparent that a woman's traditional identity in Indonesian society is tied up with, and cannot be separated from, their roles as a mother and/or wife.

In the following section, I present the second subtheme: 'change of the established roles and responsibilities in the family'.

4.2.2 Burdening others: '*Everyone has to do plenty of work!*'

"If I need to go to the hospital, who should take care of the children? I feel that it was less convenient to leave the children under the supervision of others because the kids have always been with us. We are the persons that know them best, how we raise them, so it was a bit ... a bit difficult, you know." (Meli, Minahasan, 36)

Throughout the interviews participants reported that heart disease challenges family harmony, particularly in the aspect of family's habits/routines, as well as imposing burdens on their family members. One of the main consequences of physical incapacity has led to the reduced ability of the participants to perform their social roles. Since experiencing illness, many of the women suggested that their previous social roles began to change or even ceased altogether. This reduced physical ability created limitations for the women, preventing them from engaging in activities that were routine prior to their diagnosis.

Claessens et al. (2005) confirms my study's finding that congenital heart disease does not merely affect the patient's everyday life but also the life of family members. In a study of the experiences of Iranian patients with ischemic heart disease, Moeini et al. (2012) noted that women experienced various types of changes in their life and in their mutual communication with others. Kristofferzon et al. (2003) noted the importance of providing support for women with heart disease, as they experience conflict between their roles as a wife, mother, and caretaker on one hand and their independence on the other. Findings from the current study suggest that home and family are central to the participants' lives. The traditional ideology has viewed the home as the private domain of women and considered the public domain as the men's space (Darke, 2002). This stereotype is also still evident in this study, which indicated that all participants regardless of age, employment status, religion, ethnicities, or

geographical location considered themselves as the primary carer and nurturer of the nuclear family. The husband, or the man in the house, was seen as the head of the house and the primary earner. Although, in reality some women were the primary earner in the family, household affairs were still their primary responsibilities.

The participants expressed their agreement that, as a woman and wife, they play a lead role as caregivers for the family. Based on a previous study conducted by Dewi et al. (2010), women from different levels of socioeconomic status in Indonesia, agreed that in addition to their domestic and occupational tasks, they are also responsible for carrying out caring tasks for the family. However, there is evidence to suggest men also assume fewer responsibilities, both in the partnership and household activities, when they experience severe cardiac symptoms (Bjarnason-Wehrens et al., 2007). Hence, in the situation where the lead caregiver of the family is experiencing heart disease, the established roles and norms in the family are also challenged. Being sick means that the patient may temporarily or permanently lose the ability to be the lead caregiver for the family. This situation has caused participants to feel that their illness places an extra burden on their family. Norma explained:

“When I collapsed, everyone has to do plenty of extra work, like my husband, he struggles to do the daily chores. Yeah as we know that chores are not their ‘things’, right?” (Norma, Javanese, 30)

Likewise, Ambar made similar comments,

“Of course, I feel sad. Yeah I feel uncomfortable. I feel sorry for my husband as no one be in charge of the household chores. Well, although sometimes he helped me to clean the house, it is still different, right? It just doesn’t feel right...” (Ambar, Banjarese, 46)

The inability to carry out their domestic tasks causes the women to feel profound guilt. They feel this way because the participants considered housework as solely their responsibility, so that they cannot imagine anyone else, particularly their husband, carrying out the task. These situations have created uncomfortable feelings for women, resulting in them feeling less useful than before their heart issue; or as some of the respondents have said: “useless”. Furthermore, the women also expressed that

their illness has caused arduous and continuous obligations for family members. One participant noted that:

“I feel like I am burdening my family a lot. I feel pity for them. I should be able to help my parents or help my husband. Now my husband is always helping me to do everything, taking care of me. I am so grateful that he doesn’t complain at all.” (Hana, Sundanese, 36)

Hana’s account highlights how she felt guilty, as she was no longer able to carry out her expected roles and obligations as a good wife. For Hana, being a burden means being unable to help her parents and to fulfil her responsibilities to her husband. This perception is in line with the assertion that a sense of becoming a burden consists of two significant features: a) becoming more dependent and b) being immobilised (Charmaz, 1983).

Some participants reported that they felt uncomfortable when their children tried to help them with the work around the house, because they believed that this task should be theirs as mothers. They said it was difficult for them to let others take over what they traditionally saw as their own chores. This attitude is in line with the assertion from Ronen (2016) who noted that in Indonesian society a mother plays a central role as the caretaker and housekeeper of the family. Therefore, performing domestic roles should be a mother’s primary duty and it was perceived as inappropriate to pass those responsibilities to the children. One participant stated:

“I wish I would be able to do the housework soon. I feel pity for my son. He cannot do anything as before because he takes care of me. He quit his job because I am ill, what can I do? [...] Yeah it gives me uncomfortable feelings.” (Manurung, Batak, 66)

Likewise, Lilis made similar comments,

“I am feeling pity for my kids. Now they always help me sweeping and mopping the floor, cleaning the dishes, etc after school.” (Lilis, Sundanese, 41)

These findings show how the participants grieved about burdening their families and losing the ability to do work around the house, as they did before their illness. Lilis' account illustrates how women in this study perceived the cleanliness of the home as their primary responsibility. Therefore, when someone else took over the task, Lilis felt she was being a burden to her family. The findings of this study are consistent with previous qualitative studies conducted in the UK by Pattenden et al. (2007), who noted that participants described a sense of being a burden to those around them, but also agreeing that it would be worse if they were alone. Fear of being a burden has become a sustained theme in the literature of women with chronic illnesses. In a case study with three women in the terminal stages of cancer, ALS, and heart failure, it was found that minimising the burden on their caregivers and maintaining a positive attitude was extremely important to them (Johnson et al., 2007).

The interviews revealed that most of the women (>90%) in this study had to wait over six months before receiving cardiac surgery due to limited hospital capacity. This long waiting time leads to a prolonged period of discomfort and causes yet more restrictions in women's lives. During this waiting period, therefore, the women become ever more dependent on their families. One woman remarked:

"I felt that time was running so slow and so long. First, because I had difficulty in sleeping. Second, I also could not do anything at home as before. I became very dependent on my husband nor could I take care of my kids. I mean, there were so many things that I could not do like before, like when I was still healthy." (Meli, Minahasan, 36)

It is evident that participants were no longer able to fulfil their previous roles and obligations as a good mother/wife. Throughout the interviews, the women frequently emphasised the importance of fulfilling their domestic duties and roles in order to keep their identities as a good woman/wife, as well as to maintain family harmony. The limited ability to perform routine activities, therefore, leads to frustration and a significant loss of confidence; ultimately this difficult and challenging situation causes patients to question their own identity and self-esteem. Fear of being a burden has become a sustained theme in the literature of patients with life-limiting illnesses.

All women in this study lived with their spouse/significant other or extended families; thus, they had a network to help them to complete household tasks. However, being unable to fulfil their duties as a mother, wife, grandmother, or daughter makes them feel sad and unhappy. The participants worried about burdening relatives with their dependency. They feel that their medical situation has managed to disturb everyone's life, particularly disrupting their family's harmony. A similar finding was reported by Bosworth et al. (2004) in a study of male patients with congestive heart failure (CHF) in the USA, where the men also experienced profound guilt and anxiety over being a burden to their family. In this study, women's self-image as independent, active, and strong has been transformed through 180 degrees to where the women saw themselves as a dependent, inactive, and weak. This condition has given them a sense of shame and low self-worth.

In the following section, I present the strategies the women used in order to cope with their condition.

4.2.3 Making meaning of the situation: *'It's a test from God!'*

The inability to perform social roles, as well as to live up to expectations that define their core self as a good mother and wife, causes a threat to the women's sense of self. To cope with their situation, the women revealed the importance of developing religious/spiritual coping strategies. By accepting their condition and attributing their limitations as a test from God, women were able to deal with hardships and miseries. In the participants' narratives, heart disease diagnosis carries a negative connotation that is associated with fear, hopelessness, and death. However, statements like, *"Don't be afraid, just pray"*, *"God always hears our prayers"*, *"I leave my fate to God"*, *"Just pray, I believe there is a miracle"* were prevalent in the participants' stories. These findings are consistent with previous studies that reported religion and spirituality were crucial factors in coping with cardiovascular disease and its symptoms (Seah et al., 2016, Najafi Ghezeljeh et al., 2014).

44-year-old Ratri lives with her teenage daughter and her husband. She used to be a very active person prior to discovering she had heart disease in 2014. She worked as a full-time cleaner in the same company as her husband but, post heart problem, is currently taking temporary leave. After she underwent treatment for three months in the local hospital, the doctor sent her to the National Cardiovascular Centre in Jakarta.

When she started her treatment there, the cardiologist informed her that the only way to cure her condition was cardiac surgery. Being told about the surgical intervention made her very sad. However, she then met and interacted with many other patients during her regular check-ups. She commented:

“I met many people here... it turns out that, there were many people who were in a worse condition compared to me. I was still able to walk around by myself, what about the others? Many of them were weak, with severe conditions, Alhamdulillah (thank God) I still have the strength, I always feel grateful to Allah. I always believe in Allah.”
(Ratri, Sundanese, 44)

The analysis reveals that the participants still show their gratitude to God even in the worst situations. The women tended to compare their situations with others who were worse off than themselves, and that made them felt grateful in the midst of their suffering. It is apparent that despite the hardships and miseries experienced by the women in this study, they did not attempt to question or blame anyone but accepted their suffering with gratitude. They were able to handle an uncertain future because of their predominantly Muslim faith. Showing gratitude under challenging times becomes one of the strategies to endure hardships. Norma explained:

“Thank God (Alhamdulillah) that my husband still accepted me despite my condition and illness. I learned from other patients here that mostly their husband left them because of their condition to marry other women. Our neighbour was also the same. So, her husband had an affair with another woman. However, Alhamdulillah (thank God), I mean, it makes me feel grateful for what I have, my husband remained faithful to me. He did not leave me for another woman. He accepted my condition, and he always helped me to go through all this mess.”
(Norma, Javanese, 30)

Meanwhile, Ratri commented,

“Unlike most people, I’m not afraid to die. Yeah, I am not afraid to die. ‘Are you not afraid, Mum?’ once my daughter asked me as she was

scared too. Why? I told her. You know what, either having surgery or not, all of us are going to die eventually. Even when we are just sitting like this, who knows if suddenly I fall and die here? 'Mum, why are you saying such a thing?' Yeah, I am ready to die. So I said, whether I'll go to heaven or hell, lillahita'ala (Arabic translation for I am doing everything for Allah or because of Allah). I said that I am sure, I was never afraid to die, mainly because of the surgery. No, I am not afraid at all." (Ratri, Sundanese, 44)

The majority of the participants in this study had a positive attitude to death as a result of their religious beliefs. They described that they were not afraid of death. Submitting to the will of God is necessary to achieve emotional and physical well-being. In Indonesian culture, people believe that there are three keys to happiness: i) prayer (*berdoa*), ii) being grateful (*bersyukur*), and iii) surrendering to God's will (*berserah*) (Pitaloka and Hsieh, 2015). The research data illustrates that the participants' spiritual and religious beliefs play a major role in shaping and guiding their decisions to seek treatment. Their conviction that their life is in the hands of God encourages them to undergo heart surgery, despite their fears of the risk of cardiac surgery itself. Diana explained:

"I just surrender to God, what God wants from me, how He shapes my path. I just hope that since God has given me many children, I believe that He would give me life too, a long life so that I would be able to look after my children until they reach adulthood, until they are successful in life. That's my prayer all the time..." (Diana, Bataknese, 42)

Diana shows a sincere submission to the will of God through her narrative that helped her to worry less about her condition. She coped with her illness by recognising that the illness was part of God's plan for her. Many participants expressed similar statements; they frequently stated: *"I believe that Allah always has the best scenario for us."* Their faith in destiny enabled the participants to maintain a sense of value, despite their unfortunate situations. They come to terms with their illness situation and can accept living life with it. Each woman's journey from the initial response to this new phase was long and hard. To cope with this situation, most of the participants relied on their faith to get them through the hardships: *"For me, my principle is, I have*

already done my best, I'll let Allah do the rest." The importance of spirituality most probably emerged from their inability to control all the aspects of their lives. Nineteen of the participants, regardless of their religious beliefs, rely on religious practices and spiritual beliefs to deal with the onset and recovery from cardiac disease. Dirga explained:

"Well, initially, it was hard for me. I kept asking Allah, is it true? I mean this is heart surgery, you know. I was so worried and uncertain. Thus, I decided to ask for an advice from 'pak Kyai' [a Muslim leader someone who possesses spiritual strength and wisdom]. I went to see him. He told me that I should do the operation. He assured me that everything would be okay. Then he advised me to perform istikhara prayer if I still had any doubt about the procedure [istikhara: is a prayer recited by Muslims when in need of guidance on an issue in life]. Indeed, I followed his suggestion. I performed istikhara prayer so that the procedure would not harm me... After istikhara, I felt like I got the answer, and I felt certain that I had to do the operation." (Dirga, Javanese, 30)

Numerous studies reported the importance of religion and spirituality as the primary sources of coping with chronic diseases. Islam is the dominant religion in Indonesia, and Islamic teachings help in forming an approach to spirituality. In Indonesia, religion and culture are intertwined with the lifestyle of the people, and religious beliefs have an important role in the lives of Indonesian people, particularly when under chronic forms of stress. These findings are consistent with the findings of the previous study of men and women with heart failure in Iran (Shahrbabaki et al., 2017). The researchers reported that participants' faith in God reinforced their positive attitudes towards life, providing a source of comfort to cope with life-threatening heart problems, as well as preventing feelings of desperation. Several women in my study suggested it was a miracle from God that they were still alive after being so sick initially. Rosi, a 61-year-old widow with five children, described her feelings:

"After I underwent my heart surgery, I felt like dreaming, it was just like a dream when I had been through the surgery. That was a big procedure, right? I could die there, but...it's so unbelievable that I

survived. Thank God that I feel much better now.” (Rosi, Minangkabau, 61)

Likewise, Ori explained:

“I always woke up late in the night to do a special night prayer. I always asked for Allah’s guidance. There was no other place to complain but Allah. Thank God (Alhamdulillah)! He answered my prayer. I am feeling much better now!” (Ori, Sundanese, 43)

The participants described that they tried to improve their relationship with God through praying; the participants felt that by praying they hoped to get help from God. They believed that the illness comes from God, so it is only God who can give them the cure.

Sincere acceptance has helped the women in this study to deal with the misfortunes in their lives. One of the participants described her resigned acceptance of her challenging situation: *“If I couldn’t do anything, I should just live with it.”* Most of the participants agreed that God plays an active role in their health; however, they also believe that their conscious deliberation to act upon their conditions would determine their illness outcomes. Sari described her experience when she decided to have the heart surgery:

“When I was still in the local hospital, there was this patient. She told me that she does not want to do the surgery. She said that the operation is a very risky procedure and should be our last option as we might not survive it. However, I replied, “It all depends on each person, and for me, I choose to be healthy, but I don’t know about you. I want to be healthy again, and I believe that our life belongs to Allah. Everyone can die; this is the power of God. So it’s up to you, I am not forcing you to agree with me.” [...] We don’t know how long we are going to live, age is God’s will. Even if I would die on the operating table, maybe that’s the will of God, my destiny. I surrender to God. After that, she went silent.” (Sari, South Sumatran, 44)

Likewise, Nourah made similar comments:

“...life and death are in God’s hands. We’re all going to die, today or tomorrow. I hope that if I take the surgery, I will be healthy again so that I can travel to Mecca to perform Hajj. That’s my thought. Finally, I decided to do the surgery. I am so glad that it’s over now, Alhamdulillah.” (Nourah, Minangkabau, 58)

This data indicates that the participants’ understanding of submission to the will of God, the higher power, is transformed into strength to face uncertainties in life. The findings emphasise the idea that God helps those who help themselves. Therefore, participants believe that God has the power to control the outcomes of their illness and they accept their limitations as human beings. These findings resonate with assertions by Harandy et al. (2009) who looked at the coping and healthy behaviours among Iranian Muslim breast cancer survivors. They found that, although the participants believed that the occurrence of cancer as the will of God and felt powerless to change, this belief did not stop them from actively engaged in medical follow-ups and cancer treatment. Previous qualitative research among Punjabi Sikh participants in Canada also found that religious faith was crucial for the patients in making sense of their diagnosis (Galdas and Kang, 2010). Aligned with the findings of the current study, the Punjabi Sikh participants also incorporated their religious beliefs in relation to the Sikh philosophy (“responsibility to one’s self”) to make appropriate lifestyle adjustments. However, in a qualitative study of the experiences of ethnic-minority participants in accessing a CR programme in England, Chauhan et al. (2009) found that religious reasons and participants’ fatalistic beliefs were commonly cited by participants for their non-attendance in the programme.

The study findings demonstrated that gratitude to God, even in such difficult times, together with sincere acceptance of their condition, helped the women to endure hardship as well as to achieve emotional and psychological well-being. The participants in this study described their illness as part of God’s plan, aimed to test their strength. Even though they believe that God has the power to control the outcomes of their illness, they also believed that their conscious deliberation to take measures to deal with their condition would determine their illness outcome. To accomplish this, they were taking an active role in seeking help. This behaviour is in

line with the results of a qualitative study among Javanese women with type II diabetes by Pitaloka and Hsieh (2015). The researchers reported that the women believed that submission (*pasrah*) is the essential virtue the women need for guiding social interactions and maintaining harmony (Pitaloka and Hsieh, 2015). In Javanese beliefs, submission to the will of God constitutes the highest stage of faith. The study revealed that submission does not necessarily connote a passive resignation to fate; by recognising their illness is part of God's will fills women with the strength to cope with their condition. In addition, the study also reported that women's understandings of their illness intertwined with their understanding of their faith.

Similarly, in a study among patients living with advanced heart failure in Kenya, Kimani et al. (2016) reported that most participants believed that their illness was arranged by God. They were resigned to their fate because they believed that their life and death are in God's hand. Some participants, whose symptoms deteriorated despite treatment, expressed feelings of guilt as they felt they had wronged God so that now God did not help them in their time of need. Therefore, most of the participants who were of the Christian faith turned to church to find solace. However, in a UK study it was found that the spiritual well-being of people with heart failure gradually declined as their physical symptoms deteriorated; many patients explicitly doubted the existence of life after death (Murray et al. (2007) .

It is interesting to note, submission to the will of God as described by the women in this study, did not represent a resignation to fate, as is often portrayed in the concept of fatalism or inaction conceptualised in the West (Franklin et al., 2007). The existing literature suggests that fatalism encompasses a lack of internal control over external events (Davison et al., 1992), beliefs in the notion of fate, luck, destiny, and predestination (Straughan and Seow, 1998), and feelings of powerlessness, hopelessness, and meaninglessness (Powe, 1995). On the contrary, submission within Javanese philosophy is "a sign of emotional and spiritual maturity, illness presents tests and opportunities to perform cultural virtues and to validate faith" (Pitaloka and Hsieh, 2015, p. 1162). In this sense, submission requires an active and persistent approach from the individuals to demonstrate their humility. Geertz (1960), in Pitaloka and Hsieh (2015), stated that submission facilitates individuals to achieve emotional composure, which in turn empowers them to control their feelings. Handayani and Novianto (2004) asserted that submission gives strength to the

Javanese women, so that they are able to endure suffering. Similar findings were reported by Galdas and Kang (2010) in their study of Punjabi Sikh patients' experiences in a CR programme. The findings show that despite the fatalistic beliefs that the participants held, they made several dietary and exercise changes as part of the responsibility to themselves.

Religious beliefs took a prominent role in the study participants' illness experience, irrespective of their religions. Religious values have helped the women to accept their new condition, trust their strength, and cope with heart disease and surgery. This echoes previous research, which suggests that religious beliefs help individuals to cope with their disease, find a sense of well-being, and help in the decision-making for their care and treatment (Ebadi et al., 2009). It is also possible their belief will increase their emotional resilience (Sidhu et al., 2016, Nortvedt et al., 2017, Shanthakumari et al., 2014). Numerous studies reported the importance of religion and spirituality as patients' primary sources of the strength needed to cope with chronic and life-threatening diseases (Bhattacharyya et al., 2016, Oh and Kim, 2014, Rochmawati et al., 2018, Balboni et al., 2010).

Religion is a fundamental part of life in Indonesia, and this was reflected among the participants of the present study. Islam is the dominant religion in Indonesia, involving about 87% of the total population (Central Bureau of Statistics [Badan Pusat Statistik/BPS], 2010); with Islamic teachings forming an approach to spirituality. The findings suggest that the participants in this study were affiliated with Islam and Christianity. Irrespective of their religious groups, the participants explained that spiritual and religious beliefs played an enormous role in making sense of their situation. The women's conviction that their lives were in the hands of God, helped them in retaining inner peace as well as encouraging them to follow the treatment regime. However, contrary to these findings, a study among underprivileged men in Canada following cardiac surgery reported that all participants expressed a lack of control over the outcomes of their illness, which led to the adoption of unhealthy behaviour (Savage et al., 2013). Many men in Savage's study believed that their health status was out of their control due to their fate and the illness being part of 'God's will'; a perception which inclined them to adopt a passive acceptance of life's contingencies. In addition, most of the participants were sceptical about their ability to

modify their lifestyles, and so they remained unconvinced that there could be any positive outcomes of their actions.

In Savage's study, participants' fatalistic beliefs were associated with a passive resignation to their fate; an attitude that totally contradicts the meaning of 'submission' within the Javanese culture. Interestingly, in this Indonesian study, most of the participants agreed that God plays an active role in their health; however, they also believe that their conscious deliberation to act upon their conditions would determine their illnesses' outcomes. This data indicates that participants' understanding of submission to the will of God, the higher power, is transformed into empowerment. They believed that God works directly or indirectly with the medical team, making decisions for them. The participants believed that God has the power to control the outcomes of their illness and they accepted and acknowledged their limitations as human beings. However, their beliefs did not necessarily lead to powerlessness or hopelessness; instead, their faith helped them to adjust to their illness and encouraged them to seek treatment.

In the following section, I explored other strategies employed by the women in this study to sustain their positive image and identities in front of others.

4.3 'Saving face' in front of family and others

"Then if I went to a party, usually they had loud music, right? My heart was beating so fast; I could see pulsation through my clothes. However, I tried to stay calm, did not want to look panicked or something. I talked to God, please God do not make me "malu" (translation: shame) here; do not let me to faint, that would make me so "malu". Help me God! God is good. I never experienced a blackout in public. I keep everything for myself." (Diana, Batak, 42)

In section 4.2 the participants described how their illness causes disruptions in many aspects of their lives. They also felt less useful to the family and others, due to their inability and inadequacy to perform their duties as mothers and wives. The data demonstrated that the women in the current study experienced threats to their gender identity. While religious beliefs have helped the women to cope and make meaning of their situation, the participants also expressed the importance of "saving face", which is associated with the strategies to avoid humiliation or embarrassment to maintain their dignity and/or to preserve their status or reputation. According to Yule (2010),

'face' is the emotional and social sense of self. In this study, 'face' conforms to the Chinese notion of face, known as *lien*. *Lien* is concerned with one's reputation for integrity and morality (Scarborough, 1998). The main component of *lien* is the ability of an individual to live up to her or his obligations within the framework of social harmony and strict behavioural ritual (Scarborough, 1998). Hence, 'saving face' refers to the strategies that individuals use to cope with unpleasant situations, so as to prevent or eliminate any negative evaluations of 'self' (Dong et al., 2013). Scarborough (1998) noted that saving face is also known as a 'harmony-preserving' strategy.

As has been discussed in section 4.2.2., being unable to fulfil their roles as a mother or a wife, as well as feeling they are a burden to their family, has threatened women's sense of self. For some women, this condition invoked a feeling of self-devaluation and shame, or *malu* in Indonesian. Although shame appears to be a universal phenomenon, what constitutes shameful behaviour is shaped in different ways by the culture in which that person is located; in other words shame can be seen as a socio-culturally specific phenomenon (Abu-Lughod and Lutz, 1990 in Collins and Bahar, 2000). While in Western culture 'shame/shyness' is frequently viewed as a negative feeling, in Indonesian culture, to some extent, shame is collectively shared and not always perceived as being a negative feeling. Collins and Bahar (2000, p. 41) stated: "Knowing malu involves a child learning that his or her identity is bound to that of others, especially family members, because malu may be evoked by the action of a close relative."

A child who has been born into Indonesian society has been taught to know shame since an early age. For instance, a mother taught a child to feel ashamed when he/she exposed their body by statement such as "How shameful, your tummy is showing!" (Collins and Bahar, 2000). A child would be complimented when he/she shows appropriate shyness or in Indonesian: *tahu malu* (*tahu* = to know or understand, *malu* = shame). Shame, therefore, is a catalyst for modest and humble behaviour; often being attributed to self-restraint inhibiting shameful behaviour; for instance restraining anger or emotion (Collins and Bahar, 2000). Shame serves to preserve the integrity of the individual's identity and also protects the social order by ensuring conformity (Bedford and Hwang, 2003).

Hence, in Indonesian society which emphasises social harmony and group solidarity, any behaviour that calls attention to oneself is a sign that one does not “know” *malu*. Furthermore, Collins and Bahar (2000) noted that gender-inappropriate behaviour may also cause both men and women to feel shame. For instance, a woman would feel shame if her neighbours or mother-in-law saw her husband helping her in the kitchen, as it would give an indication that she does not adequately fulfil her gender role. Hence, to be seen by others to be not fulfilling their gender roles could make a person feel shame. Therefore, when the women in this study were no longer able to perform their roles in the family due to their illness, they felt devalued as a woman. As a result of such self-perception they developed strategies to deal with these feelings. Saving face is deeply rooted in Indonesian culture, as was evident in the data collected. Saving face was the driving force when the participants decided how to cope with the illness, and to cope in a way that had the least negative impact on their social image.

In their efforts to cope with the disruptions in their lives due to heart disease, the participants exercise several strategies. In this study, the strategies that women used included: ‘I just can’t sit around and do nothing!’ and ‘I keep it secret!’

4.3.1 ‘I just can’t sit around and do nothing!’

In the earlier section, the participants expressed that one of their central roles was as the caregiver of the family. Therefore, when the lead caregiver of the family was ill, established roles and norms in the family were challenged; hence it was quite likely that the harmony in the family could no longer be sustained. The data shows that many participants in this study viewed the task of maintaining harmony and social relationships between family and society as an important part of their domestic duties. Maintaining harmony in the family has been recognised as an important responsibility for a woman within Indonesian society (Sitepu, 2000). It was not only part of performing cultural norms; under the New Order regime this tradition has become law with the enactment of the Marriage Law 1/1974, as well as in chapters 24 and 25 of the State Guidelines (1989). It is stated that women were expected to dedicate their lives to the state by performing a set of responsibilities; these included: i) to be a loyal supporter of her husband, ii) producer and educator for the future generation, iii) secondary earner in the family, and iii) member of society. In maintaining a harmonious home environment typically women have to do all the housework

(Santillan et al., 2002). Townsend (2000) echoed this view by stating that women's primary responsibility is to create the feeling of order and security within the home. In preserving harmony within the Indonesian context, women are required to submit, keep quiet, and make sacrifices for the family. Peace and harmony are the ideal conditions that everyone should strive for, in which there are "no intense feelings of resentment, or at least [they] are not expressed,...where people look for compromise solutions...in order to minimise conflict within the family" (Geertz, 1989, p. 149-151).

In section 4.2.2, it has been mentioned that heart disease challenges family harmony, particularly when it comes to family's habits/routine, as the disease imposes burdens on all the family members. The consequences of physical incapacity have led to the reduced ability of the participants to perform their social roles. Since maintaining family harmony is part of a woman's responsibilities, the women in this research utilised several strategies to preserve harmony, which is complementary to their duty of maintaining their status and identity. For this reason, in this study the act of 'preserving harmony' was considered as equal to the act of 'saving face'.

One of the strategies employed by the women to maintain harmony in the family was by creating as little disruption as possible for other family members. This goal could be achieved by: a) still taking part in the family activities, b) performing small tasks, or c) not complaining too much about the effects of their condition. More importantly, the women revealed that having a sense of control over daily activities and family obligations provided them with a sense of usefulness in the family. One of the participants shared:

"My husband told me not to do anything. 'Just leave it to me and our daughter,' he said. But if I don't do anything, I will feel sick instead. I need to move, right? I replied, "let's just help each other." I'll try to do my part, handle the small tasks and leave the harder one for them."
(Ratri, Sundanese, 44)

All the women in this study, despite difficulties, tried to maintain their role as wife, mother, or grandmother to protect their families from being overly concerned about their condition. They viewed housekeeping duties as something they are used to

doing and which brings a feeling of normality into their lives. A common theme that I heard from the women in this study was:

"I just can't sit around and do nothing".

Since being able to perform domestic activities was important to the women's sense of self, maintaining a sense of control of daily activities, such as by performing small tasks in the house, or performing supervision roles for other family members, were important to preserve their identities as a good mother or a good wife. Diana reported:

"I have always been very active; I don't want to be just like other people and buy ready meals at a restaurant. I went shopping at the market either once or twice a week, then I loaded the fridge with fresh groceries. I still did most of the cooking at home, so we didn't go out to buy food. Suppose that I couldn't cook, my children would take over, they took fresh vegetables from the fridge, and cooked. By doing that, I can be sure that my children still eat healthy food too." (Diana, Batak, 42).

Dju made similar comments:

"I still managed to cook for my family, not a lot, just simple meals, such as soup or stir-fry vegetables. Yeah, I feel pity for my family, if I don't cook, what are they going to eat?" (Dju, Betawi, 62)

Dju stated that if she did not cook, she was convinced the family would not eat. However, Dju lived in an extended household with her three children, daughter in law, and grandchildren. Hence, there were other family members who were capable of cooking for the family, which showed that it was her perception of her role that was taking precedence over reality. She argued that the family liked the food that she made, and they did not want to eat someone else's cooking. Later in the interview, she confirmed it is only her perception by contradicting herself, stating that her children told her to focus on her health and stop cooking, unless she wanted to eat a particular food that only she knows how to prepare. The data illustrates how the ability to fulfil their domestic roles and obligations, as a mother or a wife, is central to the participants' understanding of living with heart disease.

Hence, keeping up their appearances was one of the strategies the participants used in order to save face in front of others. One of the participants explicitly stated that in order to keep up her appearance in front of her neighbours she had to show that she still took part in the household responsibilities and performed her roles as a wife:

“Sometimes I went outside with my husband to help him hang the washing. I just did the easy tasks, such as giving him the hangers, and he would hang the clothes. Just to give the impression to our neighbours that I still did my duty as a wife and helped my husband to do the chores.” (Norma, Javanese, 30)

Becoming a subject of gossip in her neighbourhood, as well as being judged a lazy wife, made Norma feel uncomfortable. In her attempt to maintain a regular domestic image, Norma performed some domestic duties in the public space. Norma’s story reflects that performance of self is required, in order to keep her identity as a woman intact within the context of Indonesian society.

The participants explained that they sincerely accepted the illness, but also resisted abandoning their family and social obligations. Seven of the participants in this study, who were in a higher socioeconomic status, stated that they employed a housemaid who helped them to do domestic tasks, such as cleaning, cooking, and washing. With their health condition, the women stated that they were physically helped by the presence of a maid in the house. They stated that as a manager of the house, they were still in charge to supervise the maid every day to make sure everything was in order; hence, the maid helped the seven women to sustain their central role in the family. However, the majority of the women in this study could not afford to employ a maid/domestic servant. Therefore, they still did the cooking, although some of them shared that task with their spouse or daughter. They also still tried to maintain a daily cleaning routine, as well as shopping. For these women to be able to perform daily chores, albeit with limited assistance from family members, makes them feel secure and able to maintain their previous identity.

In their attempt to protect their status and maintain identity, the participants tried to establish standards about when, and under what conditions, it is reasonable to accept and ask for help from others. This socially and culturally sensitive issue is similar to the study conducted among Canadian women by Helpard and Meagher-Stewart

(1998), who suggested that housekeeping activities help women to cope with illness and give them identity and self-esteem. They also reported that in certain circumstances, women try to over-engage in certain household chores, as a means of coping with disruptions in their former roles. Similarly, Svedlund et al. (2001) reported that many of the women, post AMI, in northern Sweden still wanted to perform household tasks; they found it difficult not to become involved in the housework duties, regardless of their condition. Despite her deteriorating symptoms, Meli decided not to ask for help and managed the household tasks and childcare duties on her own. She expressed that it was not good or convenient to be dependent on other people, or imposing burdens on her family. She shared her story as follows:

“...and ever since they were babies, we never asked our parents to help us with the kids. We did everything on our own, so it was only recently, because my condition got worse and I had to have some intensive treatment, I asked my parents to help us with childcare.”
(Meli, Minahasan, 36)

The data show that the participants emphasise the importance of maintaining the image of a strong woman by showing the positive characteristics of self-reliance and independence in their daily activities and by meeting their social obligations. In her narrative, it was important for Meli to show that she still had the strength and energy to perform her duty as a mother. The women in this study described themselves as the manager in the house; implying they play, or at least played, a prominent role in managing household affairs. They, therefore, regularly described their struggles to accept help in accomplishing everyday tasks. Despite their condition, they tend to show strength in front of their family and others. One participant, who had a college degree level education and a professional job as a manager, stated that maintaining her roles in the family can be achieved by giving both attention and affection:

“For me personally, I still tried to serve my husband, serve based on my ability. Although I am sick, I try to do the things that I can do for him, as long as it's not too hard. In terms of sexual relationship, the doctor has told us about it, so he understands. We still support each other. By showing affection towards each other, it is the same thing, right? It's not only about sex. As a mother, in terms of my role as a

mother, I have always been trying to give them attention and affection. For example, although I am sick, I tried to act like when I was healthy.” (Regina, Jakarta, 53)

Further, Regina described that another strategy she used to retain her pre-diagnosis identity was to remain in her paid job. Her job gave her value and meanings. Although during the acute period of her illness she worked from home, she stated that she felt responsible for the livelihood of the other employees, as she was in charge of the salary payment.

The findings indicate that the women in this study were concerned about the importance of maintaining their independence to save their face in front of their peers. For them, being independent refers to being self-reliant, being strong, and being responsible. Being independent was demonstrated through their ability to perform day-to-day tasks, despite experiencing physical limitations. In this sense, maintaining independence was important for the women to maintain normality, keep up appearances and, most important of all, to avoid being undervalued by others that led them to question their self-worth in both family and society.

Suffering from the illness was not only challenged the women at the individual level but also at the familial and social levels. In addition to their illness, women in this study were aware of the expected roles they must perform to maintain harmonious interactions with their family and the others. Women are continually expected to engage in activities directed at maintaining good relations. For that reasons, rather than focusing on their own needs, the participants emphasised the requirement to consider other people's feelings and the needs of others. In that way, women attempted to maintain inner peace, as well as avoiding conflict in their day-to-day interactions. One participant stated:

“My husband [now ex-husband] never helped me. If he did the laundry, he would only wash his clothes. I know, he was a heartless person and never bothered to help me deal with the housework. But I didn't say anything to him, I just accept it, maybe this is my destiny.” (Titi, Javanese, 36)

Meli just had given birth to her second child at the end of 2011 when she discovered that she had a heart problem. She emphasised the importance of maintaining good communication with her husband to avoid friction and conflict in their relationship, as well as to achieve a sense of understanding. She admitted when she was in a low condition, she became more susceptible to mood swings, which were taken out on her husband and children because they are the closest persons to her. However, she realised that her husband and her children have always been very helpful to her. She said:

"I need to remember that my husband has helped me a lot to go through this. He knows my condition very well. Thus, we always try to talk, to communicate to find the best solution on how we should share our responsibilities. Although sometimes it's not easy because he is in full-time employment." (Meli, Minahasan, 36)

Likewise, Norma explained about her husband:

"He was so helpful when I was sick; he did all the housework. I think no other man would have done the same. In return, I tried not to bother him too much. I didn't complain too much, I mean I should try to be independent, right?" (Norma, Javanese, 30)

These findings demonstrate the women's effort to control balance and maintain harmonious relationships among family members, by restraining and controlling their emotional responses. In Indonesian societies, complaining about things that cannot be changed is considered disruptive to the group and also perceived as bad (Collins and Bahar, 2000). By not complaining too much, Norma shows how she willingly accepting the hardships and misfortunes in her life as well as trying to not put anymore burdens on her family. According to Werner and Malterud (2003), women who complain and talk too much about their pain will receive a negative stigma, as having imagined pain caused by their inability to cope with their health disorders.

4.3.2 'I keep it secret!'

Many participants reported receiving support and empathy from family members and friends (relevant others) after being diagnosed with heart disease. However, one

participant reported hiding her symptoms from everyone except the healthcare providers directly involved in her treatment. Other participants chose not to share details of their health conditions with people outside of their household. For the participants who kept their health conditions from the family, they were concerned that their symptoms would interfere with household duties and caring for others. One of the secretive participants described how she never spoke of her illness with anyone, including her children, and always tried to act like a normal person in performing her daily activities. When asked, what prompted her to do so, she answered:

*“Well, because I feel pity for my children. I don’t want to let them down!”
(Ambar, Banjar, 46)*

By revealing her illness to her children, Ambar was afraid to let them down. Participants perceived the heart as the centre of their life. Therefore, they defined heart disease as a severe illness (*sakit parah*) with an immediate threat to life; thus revealing the illness to their family members would make them worry. This attitude is in line with the findings of Dewi et al. (2010) who reported that Javanese people perceived heart disease as ‘*dangerous*’. Revealing the illness to the family would also significantly disrupt family harmony. Diana stated:

“When my husband asked what’s wrong with me, I told him maybe my cholesterol level was increased. I hide the truth from him. [...] I didn’t want him to worry about me. Because the heart is the centre of our lives... if he knew it, I was afraid that it would be burdening him. [...] If I told anyone about my illness, told them that I was sick, where would we get the money for my medical treatment? They would get mad at me...so I preferred to stay quiet, surrender to God’s plan, what God wants with me...” (Diana, Batak, 42)

Diana’s narrative above describes her fear of being a burden to her family; a situation that would ultimately disrupt her family’s harmony. She was reluctant to talk to anyone about her limitations because she was afraid that her symptoms would turn her into a burden and source of stress for others. These findings suggest that the participants struggle with diverse issues (i.e. financial hardship, and personal relationships) in everyday life, as part of their illness experience. The narrative above indicates how

the respondent was concerned about the financial situation in her family. By revealing that she was ill, she was afraid that she would disrupt the family's harmony. The findings are consistent with study conducted in Australia, which reported that women were concerned about being taken care of by others, as caring for others is traditionally seen as a woman's role in the family (Davidson et al., 2008). In her narrative, Diana shows a considerate action in which she carefully considers her husband's situation before sharing her problems or concerns. This notion of consideration becomes a mode of life to ensure that social interaction does not interfere with the interests of others. Dewi et al. (2010), in their study of the perceptions of CVD among Javanese people (Indonesia), found that balance and harmony are central to the participants' understandings about disease, health, cures, and ways of managing cardiovascular illness. As has been mentioned earlier, maintaining harmony in the family was women's responsibilities. Consequently, when there is a disruption in the family harmony, it would be targeted as the failure of the women to protect the family. For this reason, maintaining family harmony was also an effort by the women to save face in the context of both family and society.

Another participant described that one of her reasons for concealing the symptoms of heart disease was because she fears of losing her job if her employer were to think she was weak. It would very damaging for her to lose her job, as she is the primary earner in the household. Therefore, the women in this study tried to act normally and conceal their health condition or adopt what Goffmann (1963) refers to as 'passing'. 'Passing' is a strategy to escape stigmatising experiences by avoiding disclosure of one's illness to, or in front of, others. Adopting this technique is designed to protect the sick person from embarrassment or any other negative consequences. Titi has been working in a sock-making factory in Jakarta for the past seventeen years. During a routine medical check-up in her workplace in 2007, Titi discovered for the first time that she had a heart problem. Following the discovery, Titi asked the company doctor to keep knowledge of her illness from others, including the company management. She explained:

"I keep it secret. I never told anyone especially people in my workplace. I was afraid of being fired, or something, so I never, never talk about my heart disease to anyone."

She then elaborated:

“So I’m not only hiding my illness from others but I’m also not telling anyone about my marriage problem. None of my neighbours know about it [...] I feel “malu” by the fact that my husband cheated on me, and I am a sick person too. Ah, I hope no one would know about it, so I kept it all to myself. (Titi, Javanese, 36)

Despite her fears of losing a job, the account from Titi illustrates that she was more concerned about what the others might think of her, than her as a patient being concerned about of her own suffering. The feeling of “*malu*” kept Titi from openly discussing her domestic problems. She felt ashamed of her condition, both because of her illness and also her marital difficulties. Despite her husband’s attitude, she deliberately chose not to share details of her internal family conflict to anyone because she wanted to maintain her identity and status in front of others. She does not want to humiliate herself in front of others. For Javanese women, disclosing pain or complaining about feeling weak shows a lack of ability to meet one’s obligations. Those who are ill would be concerned about losing standing in front of the others as the result of a failure to live up to established socio-cultural expectations appropriate to their position, role or status. Many of the participants were anxious about their integrity in the eyes of others and acted accordingly to protect their status. By revealing their illness, or internal conflict in the family, the participants could no longer protect or maintain their credibility and status in society.

Other participants describe their experiences of keeping their illness from other people. Despite being the subject of gossip in her neighbourhood because letting her husband take over most of her household duties, Norma preferred to keep quiet. She and her husband agreed that there was no benefit in telling their neighbour about her illness. They believe that ultimately people will know the exact condition without having to explain it to them. She said,

For some people who knew my condition, they understand, but for some other who didn’t know anything...well you know this kind of neighbourhood, there will always be ‘neighbours whispers’ (Indonesia translation of ‘bisik-bisik tetangga’ means gossiping). It’s okay, in the end, they

will know the truth. My husband also became the subject of gossip, because he didn't hang out with the men in our neighbourhood that much. When he had days off from work, he helped me with the housework. [...] My brother-in-law told them that I am sick so my husband needs to take care of me. They went silent. In the end, they know about my condition. (Norma, Javanese, 30)

Likewise, Meli made similar comments,

Many people asked me that question. Sometimes before answering, I will look at the person first...if she just randomly asked, then I didn't bother to explain about my condition... but if they look sincere, then I told them the truth. However, it was tiring you know, because every day there must be someone who asked me similar questions over and over. I feel exhausted not only physically, but also mentally... Ah, it's tiring to repeat the story over and over again. (Meli, Minahasan, 36)

The findings in this study clearly indicate that participants preferred to hide their illness from those they did not want to disclose the news to, particularly outsiders. Some participants chose to distance themselves from outsiders in their efforts to keep their illness a secret. However, disclosure to husbands was implicit and evident in most the participants' reports.

4.4 Chapter Summary

In chapter 4, I have argued that the women afflicted by heart disease experienced a threat to their gender identity and social position as a result of their inability to fulfil their duties as mothers and wives. The changes in household roles, due to the patient's deteriorating condition caused by their heart disease, have resulted in women losing control over everyday life. As the female patients in my study experienced a combination of reduced physical capacity, lack of autonomy and control, and their inability to perform former roles as mothers/wives, their over-protective families had unwittingly managed to undermine or threaten the women's sense of self and their social identity. Moreover, the analysis shows that the participants worried about burdening families and relatives with their dependency.

The feeling of being a burden to the family contradicts the Indonesian ideal of a good woman, as well as the traditional feminine role of family caregiver in Indonesian society. Women have always been taught to maintain self-reliance and to fulfil their responsibilities, both within the household and within society. In this study, the women's self-image as independent, active, and strong has been transformed, after their heart trauma, to where the women see themselves as dependent, inactive, and weak. Their condition has given them a sense of shame and low self-worth. Failure to perform required social roles, as well as to live up to expectations that define their core self as a good mother and wife, threaten a woman's sense of self. For this reason, women in the study expressed the importance they attach to saving face. Face saving is associated with the patients' strategies to avoid humiliation and embarrassment, as they struggle to maintain dignity and to preserve their reputation or status, as well as preserving social harmony.

CHAPTER 5: Findings 2

Women's attendance in cardiac rehabilitation: 'a bridge to normal'

5.1 Introduction

In this chapter, I present my findings relating to women's attendance in the CR programme, as well as the perceived facilitators and barriers to their participation.

'A bridge to normal' emerged as the major theme of women's participation in the CR programme. Experiencing a cardiac event affected participants' lives in a number of significant ways. I argued in chapter 4 that threats to their identity and 'saving face' were evident in participants' stories about their experiences of living with cardiovascular disease. The participants perceived themselves as different from who they were once, indicating that disruption to their sense of self had occurred. For this reason, women in this study developed strategies to cope with the disruptions in their lives caused by the cardiac event. In managing the illness, they expressed the importance of saving face, which is associated with the strategies to avoid humiliation and embarrassment, in order to protect their social standing and self-image, by showing strength in front of others.

The focus of the following data analysis is to explore each participant's decision to attend a phase two cardiac rehabilitation programme. Focus will be on: a) their motivation to join the programme, b) perceived benefits, barriers and facilitators of participation, as well as c) the meaning of participating in a CR programme, mainly from the perspective of gender. Although the literature demonstrates that the primary facilitator of patients' enrolment in CR programme is the referral from the physician (Dechaine and Merighi, 2017), it is still unclear how gender-related societal expectations influence women's participation in CR. In this case, applying a gender perspective is useful for understanding women's experiences and their attendance in CR. I believe that it is necessary to gain a deeper understanding of how women with cardiac disease maintain their participation in CR. Understanding women's experiences in CR is critical to developing a better CR programme that specifically meets the needs of future female patients.

5.2 Cardiac rehabilitation as a *‘bridge to normal’*

During the data analysis process, I kept asking myself this question: “what was going on here that could explain women’s decision to participate in CR programme?” The analysis revealed that women’s decisions to attend a phase II CR programme were driven by their experience of suffering from the consequences of heart disease that altered their sense of self. In addition, going through cardiac surgery was also identified as an important factor that influenced their decision to attend CR programme. Throughout the interviews the participants claimed that heart disease had affected many aspects of their lives. Recurrent statements on how heart disease affected women’s daily lives were developed into the previous theme in section 4.2: *‘threat to gender identity.’* As I used gender perspectives in understanding women’s experience with heart disease, a threat to gender identity becomes the central theme of how the impacts and consequences of living with heart disease intersect with women’s social identities. The threat to the women’s sense of self was aggravated by the changes in their established roles and responsibilities, which in turn created a sense of being less useful than pre-cardiac event.

Perception of the illness and going through cardiac surgery

Apart from receiving the diagnosis, the women described that being told they should undergo cardiac surgery was also an overwhelming experience for them. They revealed how they were frightened of what might happen to them, including fear of death and uncertainty about their future. As a result of this fear, the vast majority of the women in this study initially reacted by downplaying the surgery option and by searching for alternative treatments. However, once they realised they had no other option, they slowly began accepting the idea of an operation. Since this study was not focused on how women made their decisions to undergo cardiac surgery, the detailed of this process is not explored here.

The women experienced cardiac surgery as a critical moment, which changed the ways they perceived their lives. Many women in this study also stated that they started to ‘regain control’ following the surgery, in terms of the improvement to their physical health. They described how they were no longer experiencing shortness of breath, and had started to have a ‘healthier’ appetite. Moreover, some women described that they had better hope for the future following their surgery. However, many women in

this study expressed their fears in relation to their ability to re-engage in their normal pre-event lives. Would they be able to perform household chores, participate in family and social events, or return to work? They also described a lack of knowledge on the types, doses, and intensities of physical activities that could be undertaken safely when they returned home.

For this reason, they considered that the CR programme could facilitate them to re-engage with their normal lives; particularly because the CR programme was started soon after their discharge. The timing of the CR was identified as a crucial factor for attendance in a CR programme. Beswick et al. (2005) noted that the provision of CR early after discharge may increase the rate of patients' enrolment at CR programme, as at this stage patients are still emotionally vulnerable and so, at this immediate post-op stage, they require a lot of support and motivation. Previous research has demonstrated the negative correlation between the length of waiting time to CR enrolment and enrolment rates. A retrospective study to assess the relationship between wait time and CR enrolment found that the wait time had an adverse effect on CR enrolment (Russell et al., 2011). In this sense, the long wait time to receive CR has a direct and negative effect on patient outcomes from CVD. Thus, providing patients with early access to CR capitalises on the momentum created by phase I interventions and CR completions rates are improved" (Bennett et al., 2017, p. 57).

The interviews with the women were conducted within 8-12 weeks after their cardiac surgery. By the time the interviews took place, the women described that their physical strength had improved following the surgery, for instance, they could breathe freely without any shortness of breath. On top of that, the majority of the participants reported that their physical fitness increased as a result of their CR participation. Their improved ability to move around boosted the participants' feelings of freedom, as it provided them with a sense of independence and control. Further, the participants also expressed their pleasure that they had regained their appetite, energy, and the ability to exercise.

Motivations

Almost all the participants believed that the main purpose of the CR programme was to return a person to their 'normal' functioning and to 'strengthen the heart'. From the data analysis, the core category that emerged from participants' stories was that they

saw the CR programme as one-step in their cardiac journey. The programme was a way to repair their physical and psychological health as well as away to move forward from their cardiac event by gaining the skills and confidence necessary to return to a normal life. For this reason, when asked what motivated them to engage in CR programme, twenty-three women in this study admitted that they wanted to recover so that they would be able to return to their normal pre-cardiac event lives. One participant stated:

“Well, I think it is a must, we must participate in the rehab programme, right? For us, this is also to make our heart work again, that’s good, right? [...] I want my body to be fit, after the surgery... so my heart will be normal again.” (Norma, Javanese, 30)

Perceived benefits of CR

The women in this study admitted that they faced uncertainty about their lives after heart disease diagnosis. As in the past, the participants felt restrained in their mobility due to episodes of severe illness and subsequent treatment. They described how their freedom had been taken from them and had left them with a sense of powerlessness. However, through the CR programme the participants felt that they were helped to move forward, to have a more positive outlook on their future. They experienced CR as a valuable help to rebuild many important aspects of their lives, including physical fitness, family, home, and employment. The sessions on exercise, diet, and counselling provided by their phase II CR programme provided the women with a focus and a way to introduce normalcy back into their lives.

Comments made by some participants illustrated that CR helped them with not only physical recovery, but also emotional and psychological support. The programme was helping them to regain confidence following their recent cardiac event; both physical and psychological enhancement. In the words of one participant:

“I feel that I have more hope for my future...I feel more...mmm, there are many things that I want to do...I want to go back home soon and do this and that again. That’s all. If I compare with my life before, ah...honestly, I was almost in despair. I almost gave up with my condition. However, now I feel that I can do many things again.

Moreover, after attending several sessions of rehab programme, every time I finished exercise I can do this again, I can do that again, so I feel like...mm yes, achievement unlocked. I still have many things that I want to do after returning home.” (Meli, Minahasan, 36)

Meli’s narrative illustrates a sense of accomplishment when she was able to see her progress. This is in accordance with the findings of a study among women in a women-only rehab programme in Canada (Sutton et al., 2012). They reported that the personalised exercise programme, which gave each participant a feasible goal facilitated participants to regain confidence by achieving a sense of accomplishment. Likewise, Diana stated:

“I feel much better; my health has improved a lot. Previously, it was so heavy and numb (she pointed at her chest), and so stiff, that made me scared to move, right? After I came here (the CR programme), I was not afraid anymore to lift my arms, or to move around. I learned here with the others and I practiced it at home as well. I said to myself, I need to keep my body moving, so yeah when I was at home, I folded the clothes, swept the floor, yeah I started doing small tasks again. If I didn’t participate in this rehab programme, I would be confused on how to do all of these activities, I was afraid to strain my body too much, on top of that, who should I turn to when I need information? So, I feel so grateful with this rehab programme, my sleeping has been improved as well.” (Diana, Batak, 42)

The findings show the majority of the participants stated that the overall rehabilitation programme (exercise and educational session) has helped them to make sense of their situations and provided some tools to cope with their recovery. By attending the CR programme, they gained the skills and confidence needed to return to their previous levels of activity. They felt supported by the CR staff who helped them to overcome the challenging uncertainty following their diagnosis and surgical intervention. Similar views were also described by men (Cooper et al., 2005) and women (Sutton et al., 2012), with both groups stating that their CR programmes helped them to regain their confidence that had been lost throughout the illness experience. Furthermore, Angus et al. (2018) argued that CR was often not the

primary goal for the participants. Instead, a central concern of their attendance in a CR programme was to restore their social dignity within other fields that had been affected by their illness; fields that included family, home, employment, and social life. In this sense, the findings in this study also suggest that women considered CR as a *bridge* to prepare them to return to their 'normal' lives, as well as restoring them to their 'correct' social position.

However, the three participants who dropped out of the programme offered a challenging perspective. They argued that their other health conditions made them incapable of performing physical exercises, as required at the rehabilitation centre. Sisi was being referred to Jakarta to undergo CABG after her recent MI. She only attended CR session three times before she felt that the exercise was too hard for her. She argued that her pain and discomfort limited her ability to participate fully in the exercises. She explained:

"My condition was getting worse; it dropped significantly, so I couldn't take it anymore. Thus, from the staff at rehab...I told them that I wanted to see my surgeon. I told them that, with my children also supported me. I wanted to consult with my surgeon, why my wound was so sore. So I would wait what he's going to say about that. Nah, after seeing the surgeon, they didn't let me to join a rehab programme. [...] yeah that's because my condition, my condition wasn't allowed me, because I had open wounds in my legs, so yeah it's a bit hard to walk, it was too painful." (Sisi, Batak, 67)

After attending CR sessions three times, Sisi considered herself not fit enough to follow the exercise training in rehab. Previous studies found pain and poor health to be the most important barriers to performing physical activity following a cardiac event (Fleury et al., 2004, Bjarnason-Wehrens et al., 2007). Therefore, Schou et al. (2008) argued that prior to the CR enrolment patients who suffer from additional illness should be treated for the painful symptoms, in order to facilitate full participation in CR. From Sisi's narrative, she suggested that the CR programme was not be suitable for her, as she perceived her level of fitness to be below the 'normal' range. She claimed that her condition influenced her decision to discontinue her participation. On top of that, approval from her cardiologist also reinforced her decision to quit the

programme. This is similar to the findings of a qualitative study in Scotland conducted by Herber et al. (2017). The researchers reported that the most significant barrier to CR participation was the patients' perception that CR was unsuitable for them. Participants expressed two major perceptions that influenced their decision to discontinue the CR programme; either they considered their level of fitness to be above the 'normal' range or below it.

In my study twenty-four of the women expressed that they enjoyed their participation, because they could see a possible path to recovery for themselves. Moreover, the women also discussed experiencing faster recovery, gaining strength and speed, losing/gaining weight, improved appetite, and generally *'feeling better'*. Half of the total participants admitted that not only had their health improved, but also their self-confidence and self-image. One woman said that she almost could not recognise herself in the mirror after attending several sessions of rehabilitation. She felt more convinced when her children also confirmed that she looked more beautiful than before. These changes had boosted her confidence, and she became more enthusiastic to continue her attendance in the programme:

"My children told me, 'Mama, you look more beautiful now.' I was like, how can I be beautiful? I said. At the same time, I said to myself, oh yeah maybe they're right. In the past, I was a bit overweight. My children said, 'if possible keep your weight like this Mama, don't be fat again'. And my lips, it's already... in the past it was a bit dark... Because my face was often pale. Now when I see my lips, it looks like I am putting on lipstick." (Diana, Batak, 42)

A similar experience had been described by Regina, a mother of two, who works as a warehouse manager at a packaging specialist company. She felt that the CR programme facilitated her rapid recovery. She received many compliments from her friends and families stating that she looked as healthy as before. The encouragement from her friends and families motivated her to keep coming to the programme. She explained:

"Every time they saw me, they said, oh you look healthy. You don't look like someone who just had heart surgery. [...] What they said

made me happy, and really encouraged me to keep coming to the sessions. During my hospital stay, they (friends and extended families) came to visit me more than once. They came once before my surgery, and then recently they just came and visited me at home as well. They were really surprised to see me. They told me that I had a fast recovery, that I look healthy. Then I told them, yes because now there is a rehab programme in the hospital. They were really happy to hear that. Yes, it keeps me motivated to complete the rehab programme because it helps my recovery; my health has improved a lot.” (Regina, Jakarta, 53)

Another participant described that attendance in CR helped her to improve her confidence to exercise, following the cardiac surgery:

“Before joining rehab, I worried, feared because I have no experience. I was afraid that if I exercise, the incision would open. Painful. But then look at me now. I am so happy that I actually can move around like a normal person after attending rehab.” (Ratri, Sundanese, 44)

These findings suggest that in general, the participants reported that the CR programme had helped them to build their confidence, as well as to improve their health condition. The participants believed that the programme could help them ‘become a normal person’ again. This aim would be achieved by firstly regaining their physical health, which in turn will restore their social standing in front of family and others. This finding is in line with men’s experience in a study conducted by Uren and Galdas (2015) who reported that men also agreed that CR helped them to rebuild their confidence, which in turn assisted their physical and psychological recovery. Moreover, a descriptive study by Dolansky et al. (2006) also reported that both men and women in their study identified increased self-confidence and motivation, to make lifestyle changes, as the benefits of attending CR programme.

As the analysis progressed, I became aware that there is a similarity in the constructed narrative of the women in this study. This was the narrative all 26 women shared, that of ‘self-restoration’. Their target was validated by statements such as ‘I wanted to restore’, or ‘it will help me to return to normal’ as the ultimate motives that

influenced their attendance in the CR programme. Attending the CR programme helped the women to 'restore themselves'; a development which incorporated both physical restoration, as well as identity restoration. They felt that the CR programme provided them with the opportunity to address, deal and cope with the consequences of having CVD. The programme helped the women to regain their self-confidence, which ultimately facilitated them to retake their position within family and community. In this light, CR has become a bridge across which the women can access competence and knowledge so as to re-engage with their former activities, including family, friendships, and employment. Throughout the women's narratives, I noticed that there are two distinct meanings to self-restoration: i) 'getting back to my old self' and ii) 'becoming a better version of me'.

5.2.1 Returning to my old self

In describing their motivation to attend the CR programme, many participants appeared to want to get back to their 'old selves', suggesting that there was no 'middle-ground' (new identity). Returning to 'my old self' consists of several aspects, including physical recovery, social and vocational functioning.

5.2.1.1 Physical recovery

Throughout the interviews, the participants explicitly stated that their primary goal for participating in the CR programme was to be able to achieve similar levels of activity and well-being that they had enjoyed prior to their diagnosis. Of the 26 participants, irrespective to age, ethnicity, and religion, 24 of them believed that the CR programme could facilitate their recovery process following a cardiac event. Therefore, '*wanting to feel better*', '*getting fit*', '*being healthy again*', '*to recover*' emerged as recurrent themes during data analysis. They stressed the importance of being physically fit again so that they would be able to perform their social roles in the family and society. One participant explained:

"After the surgery, I needed to prioritise myself first. They are healthy, right? I am sick; I need to restore myself first. I haven't recovered yet, imagine if I return home, then I need to look after other people (in my family)? No, I cannot do that. Prioritise myself first. Be healthy first. That's what I said to myself. If I am healthy again, I can look after my

family again. We are like a team, it's teamwork. I focus on my own health first. That's my rule, be healthy first." (Ratri, Sundanese, 44)

Likewise, Sari explained:

"I want to be healthy again, so I will have more energy to do my daily activities. I also need to be healthy for my family so that I would be able to serve my husband better. [...] I wish that I could take care of my family again. Because I believe that, a wife is the anchor of the family, right? Imagine if the wife is incapacitated. In the morning, we need to prepare everything for husband and children. As a woman, we need to deal with all the household chores, if we collapse, not strong, how are we going to deal with that? That's my reason I joined this rehab programme." (Sari, South Sumatran, 44)

Lastri made a similar comment:

"My motivation, when I return home I would be able to get my strength back. That I would be okay at home. If I don't come to the rehab, how can I re-engage with my activities at home? Yeah, I decided to complete the rehab. So that by the time I go home, I will be healthy again." (Lastri, South Sumatra, 55)

In her narrative, Sari described that her primary motivation to attend the CR programme was to regain her physical strength so that she would be able to perform her duties in her family. She viewed herself as the central figure in the home; thus, she is responsible for managing the household affairs. Since the majority of the participants were still of a relatively young age, they considered themselves as central figures in their family. The exception was made for some of the elderly participants who lived with their adult children. For them, the social expectations associated with their gender roles were a little different from those of relatively young women. This difference is due to Indonesia's cultural norms where adult children should be responsible and take care of their elderly parents.

Being sick means that the women temporarily lost their capacity to carry out this central role in the family. For that reason, many participants described that their expectations of the beneficial consequences of rehabilitation motivated them to enrol in the CR programme. They hoped that CR programme could prepare them to return to their normal life. This finding is congruent with the results of a meta-synthesis, conducted by Neubeck et al. (2012), which reported that belief in benefits from CR was one of the personal enablers for CR participation in Western countries. Rouleau et al. (2018), in their recent study, also reported that the anticipated benefits from CR had become one of the dominant factors relating to men's and women's decisions regarding CR enrolment in Canada. From the narratives of the women in the present study, it is clear that the associated physical and psychological benefits of CR have become the crucial reinforcing factors in their decisions to continue their attendance in the CR programme.

However, two participants felt that cardiac rehabilitation did not facilitate their physical recovery, thus they decided to drop out of the programme. As Desti described:

“My left leg and arm are numb and heavy because they have never been trained. If I go home, it would be trained, with hot showers and traditional remedies with leaves provided by my parents, I think I would feel better. Here? Nobody cares!” (Desti, Nusa Tenggara, 36)

5.2.1.2 Performing social roles – restore the social position

For the women who participated in this study, the significant impact of their illness had prevented them from being able to perform their normal role functions as spouses, mothers or grandmothers, as well as good members of society. This condition had a profound effect on their sense of self and invoked damaging feelings of shame and uselessness. Moreover, as domestic functions and caring roles were of high value and a central component of the participants' sense of self, being unable to perform those functions had created an emotional turmoil for the women.

The analysis reveals that the ultimate goal of each woman's recovery in this research was to be able to be part of their family again, and to reclaim their previous social roles as a mother and wife. Being able to re-engage with what traditionally has been seen as 'female' household tasks was the most critical driver of women's attendance

in their CR programme. This conclusion also resonates with the findings of a qualitative study in the US conducted by Dechaine and Merighi (2017). It was reported that with regard to the intrinsic motivation to attend CR, the women in their study emphasised their ability to reclaim their independence, not to be a burden to their family, and to improve their quality of life.

By attending CR, the women expected that they would be able to restore their former roles in the family and society that had been seriously disrupted and challenged by the presence of the cardiac event. Many participants stated that what made them continue their participation in their CR programme was their wish to return to their family and to be able to perform the household tasks again. As Sari described:

“I hope that I can get back to normal just like before... after all of this is over, I want to do things like I used to be... although before surgery, it was hard for me to take care of my family. Maybe after this I will get stronger for my family... that’s my wish.” (Sari, South Sumatran, 44)

Similarly, Ori commented:

“I want to return to normal life, I want to start my small business again; I want to make my husband and children happy. More importantly, I want to take care of my husband. Due to my illness, it’s been several years that I couldn’t fulfil my duty as a good wife. I want to do that again.” (Ori, Sundanese, 43)

The findings show that by attending CR, women expected to become ‘their old selves’, by which they meant being able to do the things that they used to do in the past. In a similar fashion, previous studies both in Western and Asian contexts noted that men’s attendance in CR programmes could also be seen as part of masculine identity restoration that had been lost through illness (Dale et al., 2015, Robertson et al., 2010).

In another account, one participant decided to stay in the programme although, to do so, she had to live far away from her family. This is a story about Susan. Susan comes from Solo, Central Java, which is about 1682 miles from Jakarta. She has four

children; the eldest is 18 years old, while the youngest is only 17 months old. She discovered that she had heart disease when she was pregnant with her last child. During her treatment prior to the surgery, she often travelled back and forth alone between Solo and Jakarta. Only during the surgery, her husband came to accompany her although he could not stay for too long, due to his work commitment in Solo. Upon her discharge from the hospital, Susan faced two difficult choices, whether she should stay in Jakarta alone to complete the CR programme or go back home to Solo. In the end, she decided to stay. She rented a room near the hospital, and she asked her mother-in-law to look after her children while she was away. She explained:

"I had to complete all these treatments. I hope that upon completion of this treatment when I return home, I would be ready. Yes, like that. I will go home when my condition has already improved, healthy again. Thus, although my husband left me here alone, I am okay with that. Moreover, I still have to continue my treatment, so that when I go home, I will be ready...ready to run my daily activities again. That's it, I want to go home when I am healthy. Thus, I will be ready to perform my daily activities and to manage household duties again." (Susan, Javanese, 44)

Susan's account indicates that she was not willing to accepting a new sub-standard identity; she was only going home when fully herself again. The findings suggest that participants were concerned about their readiness to perform their women's duties again by the time they return home. They wanted to get back to their old selves and be independent once they returned to their families. The analysis shows that after experiencing a cardiac event, women in this study expressed that they appreciated the support that they received from their family even more than before. For that reason, they valued their families so highly that they made 'living for their family' as their highest priority. One participant explained:

"I always pray to God, I would like to stay around a little longer so I can raise my children. I want to take care of my husband, that's all. Because my children, particularly if I remember the youngest one, I want to live longer. I would like to raise them until they become adults. That is my motivation, my children..." (Susan, Javanese, 44)

Norma made a similar comment:

“So yeah, I wish that I will stay healthy then I can live together with my family again, my husband and my kids. [...] I always remind myself, that I still have two small kids at home. They are still too small... and people that supported me continuously, like my husband, my mother. I don't want to disappoint them. They always supported me on every up and down, so I am not going to let them down this time.” (Norma, Javanese, 30)

It was apparent throughout the interviews that one of the biggest motivations from the younger participants was their strong desire to be able to raise their children until they reached adulthood, indicated by their children's marriage. *“I just want to look after my children until all of them get married,”* Lastri stated. For the senior participants who were above 60 years old, their goal was to be able to take care of their grandchildren.

5.2.1.3 Returning to work

Some of the research participants, particularly those who were less than 60 years old, explained that one of their primary motivations for attending cardiac rehabilitation was to be able to work again. Hana explained:

“If I am able to do my daily activities again, maybe I would be able to earn money again. So, I would be able to help my parents again, right? Because they were retired and had no income, and indeed as they worked in the private company so they didn't get any pension money. That's why now my parents really depend on the children in terms of financial support. So, I should help them, to fulfil their daily needs. (Hana, Sundanese, 36)

Similarly, Titi described:

“This is a preparation before I return to work, so I wouldn't be shocked when I start to work again and also for my experience. Who knows that

I will meet someone who has a similar experience like me, so I can share my experience with them.” (Titi, Javanese, 36)

Lilis, one of the other participants, explained that she felt sorry for her husband as she could not help him to earn money to meet their family needs. Djajaningrat-Nieuwenhuis (1987) argued that to be considered as a good mother, *ibu* in Javanese culture, a woman should perform dual roles, including caring for the children as well as working to increase the household income. Lilis commented:

“I want to have a fast recovery. Someone told me that at least we need a year to be fully recovered. A year is too long, right? I want to work again. At least I can contribute to the family income, to get some pocket money for our children.” (Lilis, Sundanese, 41)

Ori made a similar comment:

“Yes, I want to make my family happy. Although I don’t earn much at least I can help my husband. I really want to work again, to open our small shop again at home. If I am healthy, Inshallah, if God wills.” (Ori, Sundanese, 43)

On the other hand, the participants from other ethnicities also reported their intention to return to work, although with different purposes. For example Ambar, who originated from Central Borneo, explained that she planned to re-initiate her business at home once she is fully recovered, so that she would not feel depressed. She reported that she had discussed this plan with her children and all of them supported her. In a recent qualitative study that explored patients’ experiences after lung transplantation in Denmark, Graarup et al. (2017) reported that male participants also expressed the importance of taking up their previous roles, over and above returning to work. The men described work as an important part of their identity as it allowed them to recreate a ‘normal’ daily life in which they can carry out their role as family providers which will give them a focus on life.

5.2.2 Becoming a better version of me

The participants agreed that their cardiac disease adversely affected them physically and mentally; thus they expressed that it would be hard to return to a similar level of activity as before. From their narratives, the experience of living with heart disease had resulted in a permanent change to their sense of who they are, and how they wanted to be. Therefore, many participants also emphasised their flexibility and capacity to grow following their recent cardiac event.

One participant described that heart disease was only one among many misfortunes and hardships in her life. Thus she described she no longer saw herself as the same person as before. She stated,

“Since we moved back from Papua six or seven years ago...there were many things...if I can say, there were too many storms that occurred in our marriage life. Starting from me getting sick, my husband also had a problem, and then there was a flood, and then my mother died; all this happened in a row.” (Meli, Minahasan, 36)

The women in this study were not only suffering from heart disease and its corresponding symptoms, but also they struggled with various problems in their day-to-day lives. Therefore, instead of struggling to maintain control over daily activities, they accepted their loss of control and created a new and coherent meaning for daily life. One participant who had been married for more than ten years, but still had no children because of her heart disease, said that she was no longer worried about this matter and stated that her husband understood her condition. She said,

“About having children, we discussed it together. It’s okay. My husband also understands my condition, I also understand. The most important thing we understand each other, right?” (Ningsih, Javanese, 33)

Further Ningsih explained that she was no longer interested to get back to work or any other social activities; rather she wanted to focus to take care of her husband when she has fully recovered. She described that taking care of her husband is more important than anything else:

“My dream, my hope, my wish, at any rate when I am healthy again, I hope that God granted me with health, I would keep myself 100% to take care of my husband. [...] So, I keep my spirit up, I have to be healthy again so that my husband can focus to earn a living for our family. And I will handle all the domestic tasks.” (Ningsih, Javanese, 33)

In addition, participants described the way heart disease has changed them to be a better person in terms of their spiritual growth, personal goals and priorities, as well as having a healthy lifestyle.

5.2.2.1 More religious

The cardiac event and cardiac surgery have heightened the participants' awareness of their own mortality. When asked about the future, the participants described that they sustained the feeling of having been given a second chance. Of the 26 participants, 20 of them discussed new hopes and dreams for their futures, which they hoped to fulfil. Moreover, the heightened awareness of mortality became a driving factor that led participants to focus on having an enhanced outlook on life, making healthy lifestyle changes, enhancing spirituality, and spending more time with their family. One of the Muslim participants noted:

“...I become a better person. What I mean by a better person is, I became more religious now, from my previous self that did not wear hijab (hijab is the head covering that many Muslim women wear); now, I want to wear hijab consistently in the future.” (Dirga, Javanese, 30).

Although there was a consensus that this priority shift was motivated mainly by the cardiac event itself, the CR programme provided the tools and insight to facilitate this change. The patients described the CR programme as a place to find new, meaningful ways to succeed in their everyday lives and to trust in their future. Their motivation came from experiencing the progress they were making in their physical recovery whilst attending the programme. The programme allowed the women time to reflect on their experience of illness and to begin making changes in manageable ways (Simonÿ et al., 2015). The events leading to, and surrounding, the cardiac events were often described as traumatic and left many of these women feeling powerless.

Reliance on help and cooperation from families and friends incurs in the women patients a feeling of social indebtedness. Seven women in this study even stated that they felt more loved by their spouse and children since they were ill. This love existed but they had not realised or recognised it before their heart disease occurred. The programme helped to mitigate these feelings of powerlessness as well as a positive outlook towards the future, so that they would be able to make 'payback' to those who had provided help and assistance to them. One participant believed that she got her second chance for a reason. Thus, she tried to get the most out of her life by focusing on the things that were most important for her:

"I feel like I am here today, I mean I could pass my surgery and all because of all the help that I received from the people around me. So I was thinking, how can I do the payback? I probably could never pay them back...but I want to have a role in helping others when I return home. In our community, perhaps I can help many people in terms of health or something... That's what I want to do now. Well, I personally always wanted to be a writer..." (Meli, Minahasan, 36)

The data illustrated that participants had learned to appreciate what they had and not take people, things, and health for granted. In her narrative, Meli expressed her desire to be a writer so that she could empower others by sharing her experience in negotiating the many challenging adjustments and transitions to be faced after the cardiac event. This scenario is similar to the findings of Fleury et al. (1995) who reported that by empowering others through sharing their experiences, their respondents hoped that their struggle would somehow help other women in similar circumstances. Similarly, twelve of the participants in my study expressed their desire to get closer to God, because they never knew how long they would live. They believed that their life in this world is only temporary, and eternal life is life after death. Therefore, despite their faith, the participants believed that they would be punished and rewarded after death for the way in which they have lived their lives. Dirga explained that she learned a lot from her illness experience. In the following narrative, she described what she learned:

"I learned a lot! First, get closer... yeah, I get closer to Allah, the creator. Second, I have become more positive, not negative... yeah not negative like before. In the past, I had a tendency to think negatively about other people, but now I have changed. What I meant is, I have become more patient...more sincere. I realise that everything that I possess belongs to and will return to Allah. That's what I have learned. [...] Now, when I wake up at 2 am, I take the opportunity to do a night prayer... yeah, I am getting closer to Allah... I feel like I get 'Hidayah'." [Hidayah is an Arab word meaning "guidance". According to Islamic belief, guidance has been provided by Allah to humans primarily in the form of the Qur'an and Sunnah of the Prophet PBUH] (*Dirga, Javanese, 30*)

Similarly, Ambar explained:

"Now we just realised, oh when I was seriously ill like this, I couldn't do anything like before. Thus, when we are healthy, we must be close to God. Be grateful. In the past, when I was still healthy, I was always busy at my work, I had no time to be grateful, I had no time to pray, to worship, or anything else. So now, when I am ill, I have plenty of free time, I feel like I've been forced to take a break from my routine and to worship God more." (*Ambar, Banjarese, 46*)

Sari also added:

"Until now, I get my second chance in life... Maybe... I want to get closer to Allah, worshipping more because this second chance is not easy to get. I had struggled a lot, right? I will be nice to everyone; I will treat them better." (*Sari, South Sumatran, 44*)

The participants' description of getting closer to God was manifested through praying and worshipping God more than they had done in the past. The recent cardiac incidents had made the women aware that death is close, and their life in this world is only temporary. The women explained that they wanted to be more serious in preparing for their eternal life after death, rather than just pursuing worldly pleasures. The manifestation of heart disease has changed the women's perspectives on life.

This sensitisation is similar to the findings of a study conducted by Shahrababaki et al. (2017) reported that the patients with heart failure in Iran also experienced mental growth and development following their illness. Suffering from the disease had increased their tolerance against problems, changed their perspectives on life, and considered the disease as a base for peace after death (Shahrababaki et al., 2017).

5.2.2.2 Live in the present

Furthermore, some participants also described how their recent cardiac events prompted them to live in the present. For instance, one participant said: *“For the future? I haven’t thought about it; most important is what we do today. I don’t want to think of what is going to happen tomorrow. No. Focus on today. Tomorrow is tomorrow.”* This attitude is in line with a recent study of participants surviving multiple rib fractures (Claydon et al. (2017). It was reported that the traumatic event had prompted the individuals to reflect on their life experiences and frequently led to a change in participants’ attitudes to life and their future.

As a result of the participants’ motivation to make the most out of their lives, some women reported that they felt more relaxed and less stressed about their future. Despite facing uncertainties about what their future might entail, the participants believed that they would ‘see the light at the end of the tunnel’. Sari explained:

“I am very happy because it’s like being reborn for me. That’s why now I am not worried too much about what the future might bring to me, especially for my daughter. Allah will always give us a way out of every problem. For example, when I need money for my daughter there would be a way. When I was sick, Allah also always helped me.” (Sari, South Sumatran, 44)

Another participant noted:

“I don’t really care anymore. Those who are rich or poor, eventually they are going to die. I want to enjoy my life despite my current condition like this. I want to live happily. It’s not because money that makes people happy, it’s not because of their position either. But, my only prayer is, God you have given me six children, please always

make my children my solace. I always pray for that.” (Diana, Bataknese, 42)

The findings have resonance with the findings of a previous study conducted by Holder et al. (2015) which indicated that cardiac events prompted individuals to experience positive, life-transforming changes during their recovery. An optimistic outlook towards life has been found to be related to increased psychosocial adjustment, reduced psychosocial distress, and renewed vigour among patients with life-threatening illnesses (Miller et al., 1996). One of my study’s participants explained how her attendance at CR helped her to deal with her negative thoughts and emotions:

“Yeah, I wish that I could overcome my negative thoughts; I mean sometimes it’s so easy to fall prey to negative thoughts or fears, so I try to fight it. I kept telling myself that I would be healthy again. I would certainly recover. That’s why by participating in cardiac rehab, I realised that my body had recovered faster, I need to train my heart again, right?” (Norma, Javanese, 30)

One woman stated that through her experiences, she discovered her personal strength:

“If I had never suffered from this illness, I wouldn’t have met with the physician and others. I wouldn’t realise that my experience... the physician told me that not everyone can survive from this. I mean, he told me that I was so strong, that I could survive this heart condition and I can have six children. He said this is a rare case. So yeah, I am proud when he told me that.” (Diana, Batak, 42)

Some participants expressed that they felt guilty about ‘neglecting’ their children, as they did not perform their responsibilities as good mothers. One participant admitted that she had lost many crucial moments with her children because she had been obliged to send them to live with her father and her sister when her condition deteriorated. For that reasons, she explained that her children would be her priority when she is fully recovered:

“When I was very sick, my children did not get enough from me. I want to give more to them, I want to make amends. Particularly for my oldest daughter, because I know that she is old enough to understand my situation thus she suffered more than the little one. [...] I just want to see my children happy.” (Meli, Minahasan, 36)

5.2.2.3 Health empowerment

Following the cardiac event, many participants in my research expressed that they had started to be more aware of their diet and promised to adopt healthier ingredients and menus, not only for themselves but also for their family. The rehabilitation programme had helped the women to empower themselves. In this sense, empowerment refers to an increased understanding of their conditions, so that the women possessed greater control to make decisions and actions designed to improve their health (Nutbeam, 1998). As one participant described:

“I feel like there are so many bad things happened in our lives. [...] First, I started to be more aware, to take good care of myself... Second, I feel like I get a second chance from God. When God gave me a chance, there must be reasons behind it; there must be something that I could share to others. I mean like my experience in the last few years when I became very sick. Well, if we could go through this and we share it with others perhaps it could give them the strength to cope with a similar situation. [...] so yeah we became more aware and started to be careful with what we ate.” (Meli, Minahasan, 36)

The participants described that CR programme facilitated them to formulate what is important for them. In terms of physical exercise, many participants stated that they learned a lot from the CR programme; as a result they stated that they are going to adopt exercising programmes once they return home. In this sense, the CR programme provided women with learning opportunities. Rosi, one of the participants who did not complete the programme, explained:

“Yea, I am afraid if something dangerous would happen. You know because this is the heart, so I was worried if I exercise too much, or

made wrong moves that would make it worse. I am afraid that it would be fatal. If I join the rehabilitation, maybe I will remember how to do the correct moves. Moving left, right, up and down... because I don't understand about health, right?" (Rosi, Minangkabau, 61)

Hana, a woman in the middle 30s, learned many things from her experiences. In the past, she was careless with her lifestyle, admitting that even though she had a medical background but she was not careful about her diet and ate whatever she wanted. She also expressed that she was reluctant to do regular exercise. Until, one day, she was diagnosed with coronary heart disease and had to go through cardiac surgery for revascularisation. She commented:

"My priority is that I am now really concerned about my own health. I want to change my previous lifestyle. I used to eat whatever I wanted, and then I never exercised; from now, I try to start changing a little. I mean, I don't want to go through surgery again [...] I just realised that our lifestyle, habits, all of that will affect our health. Just like the metaphor, 'you are what you eat. [...] I used to underestimate that. Even though I was fat, but I thought, many people are fat but stay healthy [...] now, at my age where I should still be productive, but I don't have the capacity to do anything. I got many lessons from this; I have to change my mindset, my lifestyle, and my habits.'" (Hana, Sundanese, 36)

The data illustrates how the experience of suffering from the consequences of the disease motivated participants to become more aware of how they could obtain increased well-being in their everyday lives, as well as changing their attitudes towards what was important to them. Their life-altering experiences of heart disease and cardiac surgery have caused the women to change their priorities in life. The positive changes following those traumatic events have long been widely recognised in the literature as examples of post-traumatic growth (Linley and Joseph, 2004). More specifically, this growth may relate to the concept of self, relationship with others, life philosophies, and behavioural patterns (Calhoun and Tedeschi, 2014). Also there is evidence to suggest that women experience a higher level of post-traumatic growth than men do (Linley and Joseph (2004). One participant explained:

“The lesson, I should live a healthier life, for example, healthy diet. In the past, I did not care what I would eat as long as it’s filling. From now on, I need to start a healthy lifestyle.” (Ningsih, Javanese, 33)

In addition, apart from adopting a healthier diet, participants’ healthier decisions were also reflected in their awareness of the importance of exercise. The intentions to draw up clear plans for continued exercise were highlighted. Moreover, different kinds of goal setting were reported by participants as important strategies for continued exercise after finishing their phase two CR programme. One participant indicated a desire to lose weight to avoid a relapse: *“My main concern is to lose some weight.”* Others described that they wanted to maintain routine exercising at home, after completing their CR programme. Therefore, their attendance at CR was a crucial step in making exercise a habit.

“I think this programme is good because we can monitor our health. Moreover, this programme inspires me because at home I also want to do the similar exercise as in here. Out of my rehab schedule, I started to do small exercise too, like walking in the morning. [...] Yes, indeed this is good!” (Regina, Jakarta, 53)

5.3 Contextual factors influence women’s attendance in CR

In the previous section, the motivation and perceived benefits of women attending a CR programme have been discussed. In line with the findings from previous studies, it was found that factors that influenced women’s attendance in CR are multifactorial. The analysis revealed that all the participants who dropped out of the programme lived in different islands (Sumatra, Kalimantan, and Nusa Tenggara). The participants cited different reasons for dropping out, such as poor health or other health problems, financial reasons, family reasons, distance, or the programme that did not meet the expectations. This section presents the factors that influence women’s attendance in CR, which include: a) connecting with others, b) recommendation from health care providers, c) programme related factors, d) support from family, and e) availability of financial support.

5.3.1 Connecting with others: 'being in the same boat'

In the current study, twenty participants reported that the part that they enjoyed the most from the programme was being able to meet and interact with other patients on a regular basis. By doing that they were able to share and discuss their experiences with others who knew and understood what they were talking about; not always the case in a family context. Meeting other patients with a similar condition has helped them to reduce the feelings of alienation. It also provided the women with a sense of normality. The interaction, discussion, and exchanges with peers, provided moral support to the women. Many of the women described the social support given by other participants as the feelings of '*being in the same boat*'. They saw other patients in the CR as having similar experiences, fears, problems, and needs as themselves. They explained that the mutual moral support from the other patients at the CR centre had encouraged them to continue their attendance in the programme despite experiencing pain and discomfort whilst exercising. Being able to see other patients at different stages of rehabilitation also increased the confidence of the participants. They were able to clearly see what the exercises involved and the likelihood of progress for themselves. In the interviews they frequently stated the mantra: '*if others can do it, then I can do it too!*'

The results of two qualitative studies conducted in the UK (Visram et al., 2008, Chauhan et al., 2010) indicated that women from ethnic-minorities groups or Muslims were more likely to attend the women-only CR programme. However, this was not the case in this study; when asked about their experiences of exercising in a mixed-gender group, the women in my study did not consider that as an issue. Susan explained:

"For me no problem at all. The important thing for me is the exercise training. If it's about wearing a headscarf or not, well, actually I used to wear a headscarf. But, because my husband allowed me...he said, "Because you are still unwell, it's okay for you not wearing your scarf." He worried, if I wear a headscarf, it would be difficult for me to exercise and just give me extra work you know as I have to wear this and to wear that. He said that during my rehab here and while I haven't fully

recovered, my husband said it's fine. We should be flexible, our goal was to be healthy right?" (Susan, Javanese, 44)

Another participant commented:

"I don't mind, they are like my relatives. Some are like my fathers, some are like my brothers. Yeah, we are just like family relatives. We joke with each other. Togetherness makes us happy, for us who suffered from cardiac illness. I feel happier like this, better than just staying at home alone and doing nothing. That seems useless, right?" (Ori, Sundanese, 43)

The participants also found it beneficial to be able to exchange information with other patients who had a similar cardiac experience. In this way, camaraderie with other participants has become a source of comfort as the women disclosed their struggles of living with heart disease. Our participants explained that within the CR programme, they were able to talk about their health condition in a way that was very distinct from the way they spoke of their conditions with family or friends. In this regard, they found a mutual understanding with other participants so that they were able to discuss specific problems that they faced; particularly following their cardiac surgery. On top of that, when they spoke of their difficulties or problems, their peers in the CR programme readily empathised with the experience, although they may have experienced other types of cardiac problem. Meli explained:

"I could share the experience with other participants so I didn't feel like the only person who went through this hardship. Sometimes I felt like a burning sensation here (showing the area of the incision) it was painful. If I just stay at home, I would have all the negative thoughts. But when I talked with other patients here, I realised that I was not the only person who experienced it. So, I think the rehabilitation programme is the right place for people like us. It's very good to keep us sane, we will get plenty of help because we can meet people with similar experiences and we can share. I think this programme helped me a lot to keep my spirits up. It helps a lot." (Meli, Minahasan, 36)

Likewise, Lisa made similar comments,

"I decided to join because here I have many friends, people that had gone through the same thing. So, I think it's good. It gives me spirit. It's better to join. If I only stay at home, what am I going to do? That's it. I feel better here, joining rehab, good for my body." (Lisa, Jakarta, 54)

The above narratives illustrate how the CR programme provided women with reassurance and a sense of comfort. The women felt reassured since they realised that they were not alone in their concerns and challenges. Being part of the CR group has also enhanced their ability to share their experiences with others. Our participants recounted that they often swapped stories, news and pieces of advice to each other. Ori explained:

"I talk with other people here; they are like my family now. I have many new fellas here. Yeah I feel like they are my family. One patient sent a gift for my daughter, because we are very close, like sisters. So, it's quite nice to be here. I think it really helped other patients. Because we support and motivate each other. [...] I feel like I found a new family; I found sisters. Like that. We do everything together. We joke with each other. The togetherness makes us happy, so we are not feeling alone. It is much better than just staying at home and doing nothing." (Ori, Sundanese, 43)

Likewise, Hana stated:

Initially, I thought it's only me, who experienced this massive pain, when I saw other people, they told me that they also experienced that pain too. Oh, so obviously, she also felt the same with me, I thought it was different. It's the same, I have many friends who experienced the same thing. Thus, when I talked to others, we discussed our progress. Where you are now? Oh, so basically we were at the same level." (Hana, Sundanese, 36)

The data show that interacting with others, during the CR programme, was useful to alleviate participants' anxiety and loneliness. They found comfort in the process of exchanging experience, fear, and frustration with others. It also helped the women to alleviate their experience of feeling alone (Davidson et al., 2008). One of our participant described the perceived CR benefits:

"I am happy to be here (in cardiac rehab). I am happy because I have many friends here, yeah many friends. If I just stay at the dorm, what am I supposed to do? Just daydreaming maybe, missing my children and husband back home." (Lastri, South Sumatra, 55)

Some of our participants relied on others to get information about their condition. They felt the other participants had more experience to deal with the same situations and the CR group members understand their condition far better than the women's families ever will. They found a unique two-way connection with other participants as they share a similar experience of living with heart disease and then going through cardiac surgery. Therefore, they claimed the other participants in the rehabilitation centre as their new family and friends. Ratri stated:

"I met people from Kalimantan, Jambi, everywhere, and became friends. [...] People from all over Indonesia gather here in the hospital. I didn't know them before. Then we started to share stories. What happened with their heart, we had small chat, then we also exchanged phone number. After that we started texting, calling. Even with those who already finished their programme and went home. So the benefit was I met people that I didn't know before and we became friends, family. I have more family now. Sometimes, here we hug each other, talk, lean on their shoulders, just like with our own family. That's the benefit that I appreciated the most..." (Ratri, Sundanese, 44)

Ratri's account demonstrates that friendships emerged as an important feature whilst attending the hospital-based CR programme. Likewise:

"Another blessing, I got more friends here in the hospital, and all of them motivate and cheer me up. To be particular, here in the rehab

programme, everyone knows everyone else, right? So, we motivate each other, be strong be strong...” (Sari, South Sumatran, 44)

The findings demonstrated that women valued the mutual give-and-take emotional process with other participants that was achieved through problem sharing, support and encouragement, as well as mutual understanding. These activities have helped the women to feel less of a burden because they had the opportunity to help others with similar medical conditions. In return, the women also described how they were more open to receiving support and encouragement from others. The feeling of being less of a burden and having the opportunity to help others with similar conditions helped the women to regain a sense of normalcy in their lives. Beyond camaraderie and peer support, there was also a tendency for the women to draw social comparison. Women explained that during their exercise sessions, they could compare their situation with other participants in the programme in order map their own progress and to put their cardiac event into context. Ningsih explained:

“I saw people practising gymnastics. I asked the nurses, in what stage of rehab are they, how many sessions they had attended because they were already able to do that task. Meanwhile, when I looked at myself, I was still afraid to move my body. The nurses said that it has been their second or third meetings. Oh, yeah I will be like them by then (laughing). [...] You know when we did this walking exercise, and suddenly someone overtook me, ugh that makes me ‘panas’ (note: a sense of rivalry, wanting to compete). Oh why has she passed me, I thought I started my rehab earlier than her. So, it made me more motivated to do the exercise... (laughing)” (Ningsih, Javanese, 33)

As can be seen, the use of benchmarking generated a boost of motivation within this group of women because they believed they were just as capable as the other participants in the CR programme were. Some women admitted that they felt better about their current circumstances after comparing their own situation with others in the programme. When comparing her situation with other participants in CR, one participant felt grateful that her situation was not as bad as others were:

“As you know, we are like in the same boat. When I saw another participant, and she was in more severe condition, then I looked to myself, ‘Ah, how lucky I am. I am much better than them’. No, not because I wanted to demean them, but I just felt grateful, because there were many people in a much worse situation than I was. But... God gave me, although I suffered from this disease, but I was still in a better condition than my peers were. That’s what I felt grateful for.”
(Diana, Batak, 42)

On the other hand, one of the elderly participants stated that seeing the other participants performed exercise had helped her to overcome her fear to exercise. She reported that previously she was afraid to do exercise, fearing that something dangerous would happen to her heart. She said:

“I get the experience here. Oh, so I can do this. If I was just stay at home and alone, I wouldn’t know anything. In here, I have many friends, so that I am not afraid to move my body.” (Dju, Betawi, 62)

In contrast, one participant who decided to withdraw from the CR programme argued that she did not find any beneficial impact of rehabilitation; furthermore she felt that she was different from others. Desti is an agribusiness graduate who worked as an administrator in a private hospital before being diagnosed with heart disease. It was a huge shock for her to find out that she had a problem with her heart, and still left her in disbelief until she underwent her cardiac surgery. She experienced left-sided weakness since 2015. Upon the discharge from the hospital, she decided to enrol at phase two cardiac rehabilitation. She acknowledged that her decision to engage in CR was not because of the physician’s recommendation but more because of internal motivation as well as encouragement from other patients who had taken part in the rehabilitation programme. However, after attending several sessions, she felt that the programme was not designed for people who were affected by hemiparesis (weakness in her left-side of the body) like her. She expressed her dismay and frustration that the programme did not help her to overcome her condition. In this light, the CR programme did not meet her initial expectations. Therefore, she did not consider the programme useful for her since her health had not improved since attending rehabilitation. Rather, she felt embarrassed and humiliated in front of the

other patients as she could not exercise at the same level as them. This is similar to the findings of a qualitative study conducted by Dechaine and Merighi (2017) who reported that one of the challenges to CR participation was the degree to which participants felt “different” from other members of a groups. In the following conversation, Desti explains that she might have been able to enjoy the programme if it had paid more attention to her hemiparesis condition:

“It’s good for people who do not have paralysis like me to do the exercise here. But for me, with my condition, the training is too hard to follow so I don’t really enjoy it. I want to be more focused on my paralysed limbs because I already had heart surgery. I want to recover from the paralysis.” (Desti, Nusa Tenggara, 36)

From her narrative, I noted that Desti had a misconception on the potential benefits of CR during her initial decision to enrol in the programme. She thought erroneously that the rehabilitation programme would help her to recover from her paralysed limbs. Therefore, after she attended several sessions, she decided that the programme did not meet her initial expectations. Her decision to drop out of the programme happened after considering whether the anticipated benefits of CR were worth the burden, time, physical pain, and so on. This example complements the earlier work of McKee et al. (2014), who reported that the main reasons for CR non-attendance among men and women were i) a lack of interest and b) a perception that the programme would not be beneficial.

5.3.2 ‘The doctor told me so’

All participants explained that the staff/physiotherapists visited them while they were still in the hospital, prior to their discharge. They explained that a few days after the surgery either a nurse or physiotherapist came to their bedside to help them with early mobilisation, as well as giving them information about CR. The staff explained all aspects of the CR programme to them, including; a) the component of the programme, b) the purpose, c) the duration, and d) what was expected of them as ‘the clients’. The benefits of CR, as well as the negative consequences of not following the programme, were also explained. One day before their discharge, the staff brought the participants to the rehabilitation unit to receive a one-to-one counselling session (initial orientation appointment) with the CR nurse specialist in the rehabilitation centre. An initial test

involved a six-minute walking test was performed to assess their functional capacity. Participants described that they got positive impressions during their visit to the CR programme centre and induction session, which also facilitated their decision to enrol. One woman explained:

When I was still in the ward, mm, someone came to me. He came to me and forced me to do small exercise, like this [the participant lifting her arms above her shoulders and moves them backwards and forward]. I immediately said, 'Ouch!'; but he told me that I need to practice it. [...] Then he brought me to the rehabilitation unit, and I got counselling about the programme. (Manurung, Bataknese, 66)

These findings have resonance with results from a study by Grewal et al. (2010) who conducted qualitative research to investigate CR referral among South-Asian patients. They reported that liaison referral, in which the patients had the chance to have a one-on-one discussion with healthcare professionals about CR, seemed to be the most effective way to increase CR participation. Research has shown that South-Asian patients generally demonstrate high respect to a doctor and therefore this attitude makes it easy for them to follow a doctor's advice (Kumar et al., 2004). Strong recommendation and endorsement from their physician, as well as referral from their cardiologists, nurses, and physiotherapists were cited by many participants as the reason for their attendance in CR. As one woman summarised:

"Well, the doctors told me to do so. I just followed it. Because, since the beginning, my intention was to get treatment from here, so I should obey all their suggestions to me." (Susan, Javanese, 44)

Similarly, Sisi commented:

"The patients, like me for example, of course, we don't have any medical knowledge, right? So, I just followed what the doctors said, what the nurses said..." (Sisi, Batak, 67)

Many participants reported that they decided to take the rehabilitation programme because their cardiologists told them to do so. Numerous research studies have

consistently identified referral or recommendation from healthcare professionals as an enabling factor for CR enrolment in both men and women (Galdas et al., 2018, Ades et al., 1992, Grace et al., 2002, Jackson et al., 2005, Rolfe et al., 2010). Culturally, Indonesian society generally holds health care professionals, particularly physicians, in high regard. This general notion is also common among other South Asian countries. The results of a qualitative study conducted by Greenhalgh et al. (1998, p. 981) demonstrated that South Asians viewed physicians as a *“busy, authoritative, and knowledgeable person who rarely makes mistakes and has a full understanding of the conditions he or she treats”*.

The women in this study often stated that by participating in CR their condition would be monitored by the professionals and it would be easier to gain access to their cardiologists as well. Further, the participants described that by not attending CR, it would be difficult for them to get help when something bad happened to them. Recommendations from the physician have long been known as a critical factor that influences a patient's participation in CR (Ades et al., 1992). Some participants in my research viewed the CR programme as a form of treatment, a compulsory programme following their cardiac surgery. Although the patients could not say exactly what CR might involve, they were eager to attend believing it would be of benefit. Hana explained:

“How I decided it, well first because I had received health education, and then they already scheduled it. On top of that, the way I see the rehab is like, this is one package with the surgery, so this is a must-go programme. Because the goal of the rehab is also for our benefit, right? Yeah, so it's an easy decision for me, I decided to take it.” (Hana, Sundanese, 36)

Similarly, Ori explained,

“I went because the cardiologist told me to do rehab. But I think he is right. I feel much better. If I went home directly, I think it's impossible for me to do the exercise like this. Impossible. At home, I only have a bike, and it's already in a terrible condition.” (Ori, Sundanese, 43)

The data shows that a recommendation from a physician or other allied health professionals was cited as an essential reason for the women to enrol in the CR programme. The findings of the current study are congruent with previous studies (Clark et al., 2013, Neubeck et al., 2012) that identified a written referral, complemented by a strong recommendation and education material about the importance of CR, mediates participation in a CR programme. However, research suggests that women were less likely to be referred to phase two CR programmes than men (Colella et al., 2015).

In contrast, one woman who dropped out of the programme described a contributing factor to her exit as 'the lack of opportunity to discuss her condition with the physician'. She said that '*nobody*' had spoken to her about it so that she acquired the information about the CR programme through other patients. She experienced difficulties in communicating with staff, stating that they did not provide her opportunity and time to ask questions, or to receive a full explanation of her condition. Therefore, she admitted that she still did not understand the full extent of her illness and the proper precautions she needed to take in order to prevent further damage. Burström et al. (2012) pointed out that patients not receiving adequate information led to feelings of insecurity and anxiety in relation to their illness. Therefore, the confused patient's decision to enrol in a phase two CR programme was based on the recommendations from other patients. This 'solution' is in line with the findings of a meta-analysis of women's experiences of heart disease (Galick et al., 2015). The findings showed that consistently, across studies, women expressed difficulty in gaining information about their condition from healthcare providers; or when the information was given typically it was vague or ambiguous. On the other hand, Bäck et al. (2017) asserted that the provision of consistent information from all the involved healthcare professionals was described as an important factor for facilitating attendance of an exercise-based CR programme.

5.3.3 Safe environment to exercise

Another critical finding in this study that influenced women's attendance in the CR programme was a sense of security from being in a closely monitored environment in the specialist cardiac hospital. This context gave the women a sense of comfort that they were in professional hands so that they could exercise without being worried the exercise would harm them. One participant noted:

“They were really in control of it because they are expert in this programme, right? They were very detailed and paid attention to the intensity of our exercise; they monitored our blood pressure, they instructed us to do this and that.” (Susan, Javanese, 44)

Some women expressed their concerns and fear about stressing their heart too much during exercise, that it might trigger another cardiac event. When starting their exercise programme, all the women felt some degree of vulnerability. However, they appreciated how the staff offered assistance and instruction regarding proper techniques for exercise. The staff are experts at modifying the exercise levels to meet the physical needs of each of the participants. On top of that, the staff also encouraged exercises that the women enjoyed. The individualised exercise programme gave all the women motivation and confidence to begin exercising independently:

“Yeah I would suggest them to come to the rehab... “It’s okay; you’ll be okay here. I mean here we don’t have such target you know, it depends on our condition, so take it slow.” It’s not...yeah, it’s not. We don’t have a target or competition among patients, I mean it only depends on our condition...” (Dirga, Javanese, 30)

When explaining their CR experience, many women described that it was hard to start the exercise in the beginning, because they had to deal with endurance and physical symptoms after their recent cardiac surgery. They were also concerned that the exercise regime would be too strenuous. Some participants noted concerns about pain and fatigue during their programme. They also worried when their heartbeats increased, or they became short of breath and felt dizzy during exercise. However, the CR staff explained that it was a normal effect of the training and taught them to take a regular break and not to push themselves too hard. Norma explained:

“Maybe at the beginning, I felt so tired and it was hard to manage my breathing. But after that, the second time I went to the exercise programme, or maybe not the second time, but I couldn’t remember it exactly, I felt better when I walked, it was not so difficult like before.

Then my husband told me, "Why are you walking so fast? Are you not getting tired?" "Oh, I don't know, it is much easier and lighter to walk now...and my steps were like tep tep tep... I am not tired at all. I feel much better; I breathe normally as well..." (Norma, Javanese, 30)

According to my respondents' narratives, the health professionals in the CR were also friendly, supportive, and encouraging. For example, when the participants often complained to the nurses about their condition, the nurses always reassured them and told them that their experience was a normal process of recovery. Therefore, the women in this study expressed that they appreciated the support provided by the CR staff, as they guided the CR patients in handling uncertainties and fears, particularly after their cardiac surgery. Manurung explained:

"I feel healthier, but I was worried why I often felt so weak, and this incision was still so painful every time I moved my body (pointing at her incision wound). [...] I just asked the nurse, 'what's wrong with me?' I asked her why my incision area was so painful when I was riding the car. She said, 'oh it takes time, it might take six months to recover completely.' Yeah because you know, they opened my chest, so it takes time. We need to be patient here." (Manurung, Bataknese, 66)

In addition, the participants confirmed how their continued CR attendance was influenced by the help and assistance they received from the rehabilitation staff. Many participants described the staff as being very friendly and supportive. They never forced the women to perform exercises beyond their physical capacities. The staff created a tailored programme and set goals for each patient depending on their physical condition. The motivation and support provided by staff at the CR centre were described as an important motivator for the patients' attendance in the exercise sessions. A participant's support:

"...and then the nurses are so kind, they could guide me, motivate me. They are patient too so that they could direct me. Usually, if the nurses are sharp and mean that makes us reluctant to attend the session. But this is not the case. The nurses are kind; they always motivate and

understand us. Thus, I feel comfortable to attend the session.” (Ambar, Banjar, 46)

Some women in this study reported that during their initial attendance in the rehabilitation programme, they were worried as they had never used any exercise equipment such as a treadmill or static bike. Despite experiencing a lack of confidence in their initial engagement in CR, the women still managed to continue their participation because of the assistance and support coming from the CR staff. Similar findings have been previously identified in a study by Bäck et al. (2017), which found that participants felt supported by physiotherapists in CR, when learning about the right dosage of exercise as well as reducing any fear of exercise. One participant stated:

I don't have any particular difficulty, only in the beginning because I never ride a bike or exercised on a treadmill. So, I don't know how to operate the treadmill, I am still confused. Sometimes, I still feel dizzy as well when I walk on the treadmill, maybe because I haven't got used to it. Trust me, for all my life, this is the first time I've ever used a treadmill.” (Norma, Javanese, 30)

Previous research identified gender-related barriers to CR attendance specific to women, including embarrassment and lack of confidence to perform the exercises in the CR centre. One of the participants in this study also suggested that she had a problem with performing the exercise in front of the public. However, she described that she got more relaxed after attended several sessions because of the supportive and positive atmosphere created in the CR centre. When asked of the barriers attending CR, she shared:

“Basically, I'm timid, easily frightened, and nervous especially when someone was watching me. When people looked at me, I will be very nervous. I don't know how to get rid of it. Everywhere when I get nervous, I will start to sweat a lot. But, after several times here, I start to enjoy it, and I feel comfortable here. My family even told me, how can you say that you enjoy staying at the hospital? But it's different here, the hospital is not scary like a hospital in general, you know? In

here is comfortable, I often think when I will be back here again.” (Titi, Javanese, 36)

My research findings demonstrate that the therapeutic environment is one of main factors influencing the women’s decision remain in, or leave, the CR programme. Some other women described that they were not feeling safe in the CR exercise environment; they felt out of place when exercising in a community or fitness centre, because they were slower than the people around them.

5.3.4 Family support

A large number of studies have reported that family responsibilities and obligations, including childcare and domestic duties, frequently hinder women’s participation in a CR programme (Clark et al., 2013, Gallagher et al., 2008, Tod et al., 2002, Day and Batten, 2006). However, this finding was not supported by the present study. Many participants explained that they received a great deal of support from their spouse and family members, following their cardiac event. In fact, almost all the participants that were interviewed in the CR centre came to the programme accompanied by a family member. This support not only helped them to cope with the immediate impact of their illness but also positively influenced their decision to attend the CR programme. Through interaction with their family and friends the women gained emotional and social support network and a sense of meaning in their lives. One participant, Diana, explained that she received more attention from her family members since they knew that she suffered from heart disease:

“I feel like a queen [participant laughing]. I said, God, I suffered from this disease, but my children pay more attention to me. They get closer to me. [...] that’s motivated me to recover soon, to be healthy again, because my children and my husband so care about me. (Diana, Batak, 42)

The women in this study also expressed their appreciation and gratitude not only for the material and emotional support given by their family and friends, but they also cited spiritual support as the most important support for them. Ori described notes:

“The most important support is prayer. Although my friends and neighbours could not come to see me in the hospital, all of them sent

their prayers for me so that I could recover and be normal again.” (Ori, Sundanese, 43)

For the older participants in the group, it was found that encouragement from their children became a significant factor in their decision to enrol on, and then adhere to, the rehabilitation programme. As reported by Dju:

“Yeah my children supported me a lot. Sometimes, I feel lazy to attend the session, they told me to keep continuing it. They asked whether I was exhausted or not. I said no, so they pushed me to come to the session. Everything comes from my children actually, because you know, they were supported me financially, they paid for everything.” (Dju, Betawi, 62)

Lani shared a similar experience. She explained that it was her children that insisted that she should complete the rehabilitation programme.

“The doctor said that I have to attend all 12 sessions. My children told me to do it. If they said 12 sessions, then complete all of that, until finish. So, I would have my own satisfaction as well.” (Lani, Nusa Tenggara, 58)

The participants described that they had discussed the matter with their family members first, before deciding to participate in the CR programme. For these participants, they argued that it would affect their family’s financial plan, so that it was necessary to discuss the programme with their spouse and / or children. Ori commented:

“Yeah, I had a discussion with my husband first. He then told me, ‘if this is the best for you, then just do it’. Because, if I decided to go back home directly following my hospital discharge, I need to attend the session three times a week, I think it would be harder, with the distance, and my post-op condition. So, my husband said, let’s just find a temporary accommodation first, even though we need to get some loan, but more importantly, I would be healthy first. I agreed with him,

then after that, we brought this up to our extended family members.”
(Ori, Sundanese, 43)

However, there were some participants who reported that they had chosen, or been obliged, to decide on their own. As reported by Ratri:

“They asked me, who is going to accompany me during my rehab session here? No one. Are you brave? Yeah I am. So, I joined the rehab because the location is also not too far from my relative’s house where I am staying now. My family contacted me through text, or phone call. They supported me that way, because they had to work and couldn’t come here. But, I feel that all of them were so helpful. No one prohibited me, rather they encouraged me to complete all the sessions.” (Ratri, Sundanese, 44)

Many women reported that they were highly dependent on their spouse or family members to take them to the CR programme. Therefore, the participants recalled that one of the most important support factors from their family, was the willingness of family members to make time to accompany their relative and heart patient to their CR programme. Since the patients were still weak and afraid to travel alone or to use public transport (an issue relating mainly to those participants who did not have temporary accommodation near the hospital), the family was responsible for arranging home-to-hospital-and-back transport. One of the participants who dropped out reported that despite her motivation to complete the rehabilitation, she could not stay alone in Jakarta after all her children had to return to their jobs. Therefore, she decided to drop out of the programme because she did not have any family member to accompany her.

A 61-year-old woman, Rosi, lived with her daughter since her husband died in a traffic accident around 15 years ago. After attended CR for the sixth time, she talked to her doctor about leaving the programme early because she did not have anyone to accompany her during her stay in Jakarta. Her son, who escorted her when I interviewed her, had run out of holiday time, so had to go back to work. For that reason, she sought permission from her cardiologist to make an early exit from the CR programme. She explained:

“This is because I had no one to accompany me here after 12th of August there would be no one who could stay around with me. My son had used all his holiday this year. [...] so I was a bit puzzled. Then I...I decided to get advice from my cardiologist. I met her and I consulted her about my condition. She told me that I could continue in Palembang for the regular check-ups. I followed her advice. She also allowed me to leave earlier from the rehab programme, although I haven’t finished it yet. Maybe when I go back home I would still continue to practice, I still remember the movements, right?” (Rosi, Minangkabau, 61)

These findings are consistent with previous studies that suggest elderly women were more reliant on others, than were the younger female patients; thus this reliance impeded their CR participation (McKee et al., 2014, Neubeck et al., 2012). Despite her decision to quit the programme, Rosi believed that she would manage to continue the exercises at home. To quit the programme does not necessarily mean to stop physical exercise. Being exposed to exercise in the CR programme has built up her confidence and generated enthusiasm to try exercising outside the programme.

Two participants in the present study decided to quit the programme because they missed their family back home; they were ‘home sick’. Desti, 36-years old, decided to withdraw from the programme after her sixth session because she missed her baby daughter, who was at home. In her narrative, she explained that if she could have her daughter with her, she would stay in the programme:

“If my daughter is here, I am willing to finish the programme, you know.” (Desti, Nusa Tenggara, 36)

Similarly, Eva explained:

“Because I’ve been away from my village for too long. [...] I miss my family and husband back at home. Unfortunately, my husband couldn’t accompany me to Jakarta because he has motion sickness. So, I was only accompanied by my sister and children.” (Eva, Minangkabau, 58)

The availability of adequate support from family and friends allowed the women to focus on their recovery and to attend the CR programme. Family support was frequently cited by participants in this study as significant in the way that such help a) gives meaning to their lives, b) provides the needed motivation to recover and c) motivates the patients to make the necessary lifestyle changes. The participants often said that eventually their decision to attend the CR programme was for the family's collective needs; the family would need their mother / wife when they are healthy. The family provided a reason for the participants to recover and therefore, the thought of being able to resume their roles of looking after their family, has motivated the women in this study to attend and complete the CR programme.

5.3.5 Logistical support

From the perspective of cost, the availability of insurance to cover the cost of the programme became a significant factor that influenced women's participation in the CR programme. The participants described when they received a recommendation to attend CR, one of their first considerations was the cost. And of course 'cost' not only involves the cost of the programme, but also money for accommodation and/or transportation. One participant recalled her experience:

"The physiotherapist came to my room and told me to attend rehab, he said it's a must. I asked if I don't come to rehab, what will happen to me? Because I live in Bekasi, moreover considering my condition, how can I take public transport to come here? If I had to take a cab, how much money I need to spend? But he said, it's a must, 'you don't want to suffer of the consequences, right?' He told me about blood clots, and something else. I don't want to suffer like that, so I decided to come." (Diana, Batak, 42)

The availability of insurance coverage facilitated women's attendance in the CR programme. One participant commented:

"I feel so grateful with this insurance coverage from the government. Without it, I don't think that I would have made it so far." (Nourah, Minangkabau, 58)

Ori also agreed that the insurance coverage has helped her to continue her participation in CR programme,

“Yes, everything has been covered by the government scheme (BPJS) insurance. We just spent money on our personal expenses, such as for food, etc. So my rehab is also being covered by insurance. I think the service is very good.” (Ori, Sundanese, 43).

Even though there were no direct enrolment fees, however, some participants considered the cost of public transport and accommodation before deciding to enrol in the CR programme. For the women who lived in Jakarta, the availability of family members with vehicles or public transportation was highly influential in their decision to enrol in the programme. On the other hand, participants from outside Jakarta had different concerns about their decision to participate in the CR programme. They were concerned about the extra funds needed to cover the costs of temporary accommodation during their extended stay in Jakarta. Therefore, the family's financial situation was one of the vital aspects informing their decision to participate in the CR programme.

When discussing the cost of public transport with her family, one participant said that her family encouraged her to join CR. They said that they should be grateful that all the medication and surgery cost was free and covered by insurance. Thus, they should not complain about the cost of transportation, which was nothing, compared to the total cost of the treatment. As Manurung described:

“I had to discuss it first with my children because during the rehab there are still some costs that we need to cover. Let's say for the taxi back and forth from the hospital, how much is that? In the end, my children said, 'It's okay Mum. Your surgery was for free, imagine if we have to pay for that, how much money that we are going to spend. So, for the rehab, I think it would be much cheaper than that. We can afford it...'” (Manurung, Batak, 66)

The findings show that most of the participants received adequate support from their family members to complete their rehabilitation programme. This outcome is contrary

to the findings of previous studies that reported women received lower spousal support compare to men (King et al., 2007, Astin et al., 2008, Alsén et al., 2008). In contrast, one woman who was interviewed over the phone reported that the lack of financial resource became one of her primary reasons to drop out of the programme. She explained that she did not have any insurance scheme to cover her rehabilitation costs, so her husband had to borrow money from other people. She commented:

“I had to return home because we did not have any more money to pay the cost of the rehab during our stay in Jakarta. I had no other option.”
(Nona, Javanese, 49)

5.4 Chapter Summary

In this chapter, I have presented the findings of the research that related to women's attendance in the CR programme. From the analysis, it became apparent that 'a bridge to normal', a journey towards self-restoration was the central phenomenon which influenced women's attendance in the phase two CR programme. Participants considered the CR programme as just one step in their cardiac journey. The CR programme was a means to restore the women's physical and psychological health and to move forward from their cardiac event; they could progress by gaining the skills and confidence necessary to return to their normal lives. The data demonstrated that 'returning to normal' covers two distinct meanings to the participants: i) returning to my old self and ii) 'becoming a better version of me' following my cardiac event.

There are several factors identified as the issues that influence women's CR attendance. One of the most significant factors was 'connecting with others'. Being able to share their experiences with other patients in the CR unit, as well as the feeling of being in the 'same boat' helped the women to reduce their feelings of alienation, as well as facilitating their continued attendance in CR. However, the issue of feeling different from one's peers has been seen as a significant barrier to continued CR participation. The data analysis also revealed some other factors that affected women's attendance in CR, including: i) a recommendation from health care providers, ii) having a safe environment in which to exercise, iii) receiving family support, and iv) logistical considerations.

CHAPTER 6: Discussion

6.1 Introduction

The overall aim of this research was to gain an understanding of women's experience of heart disease and attendance in a phase two cardiac rehabilitation programme in Indonesia. The main research questions were:

1. *How does gender shape women's experience of living with heart disease?*
2. *How do women decide to attend phase two cardiac rehabilitation?*
3. *What are the contextual factors that influence women's attendance in phase two cardiac rehabilitation?*

The purpose of this chapter is to make sense of the study described in chapters 4 and 5, as well as to explore the study findings in depth drawing on related literature and conceptual/theoretical thinking. Through analysing the interview transcripts from the 26 women with heart disease, a number of categories emerged related to experiencing and living with heart disease and to CR attendance (see Figure 6.1 for the overview of the study main findings). It appeared that experiencing a cardiac event had several consequences for the participants. In chapter 4, I have analysed the findings related to the impact of living with heart disease on those women's daily lives, as well as how women coped with their condition. In chapter 5, women's attendance in phase two CR programme was analysed; issues to emerge that influence their continued attendance in the phase two CR programme include: i) their motivation, ii) expectations and iii) contextual factors.

I structured the discussion in this chapter following the emergent themes from the data analysis (Figure 6.1). Each major theme will be explored in depth in relation to the research questions with a recommendation for future service provision in cardiac rehabilitation.

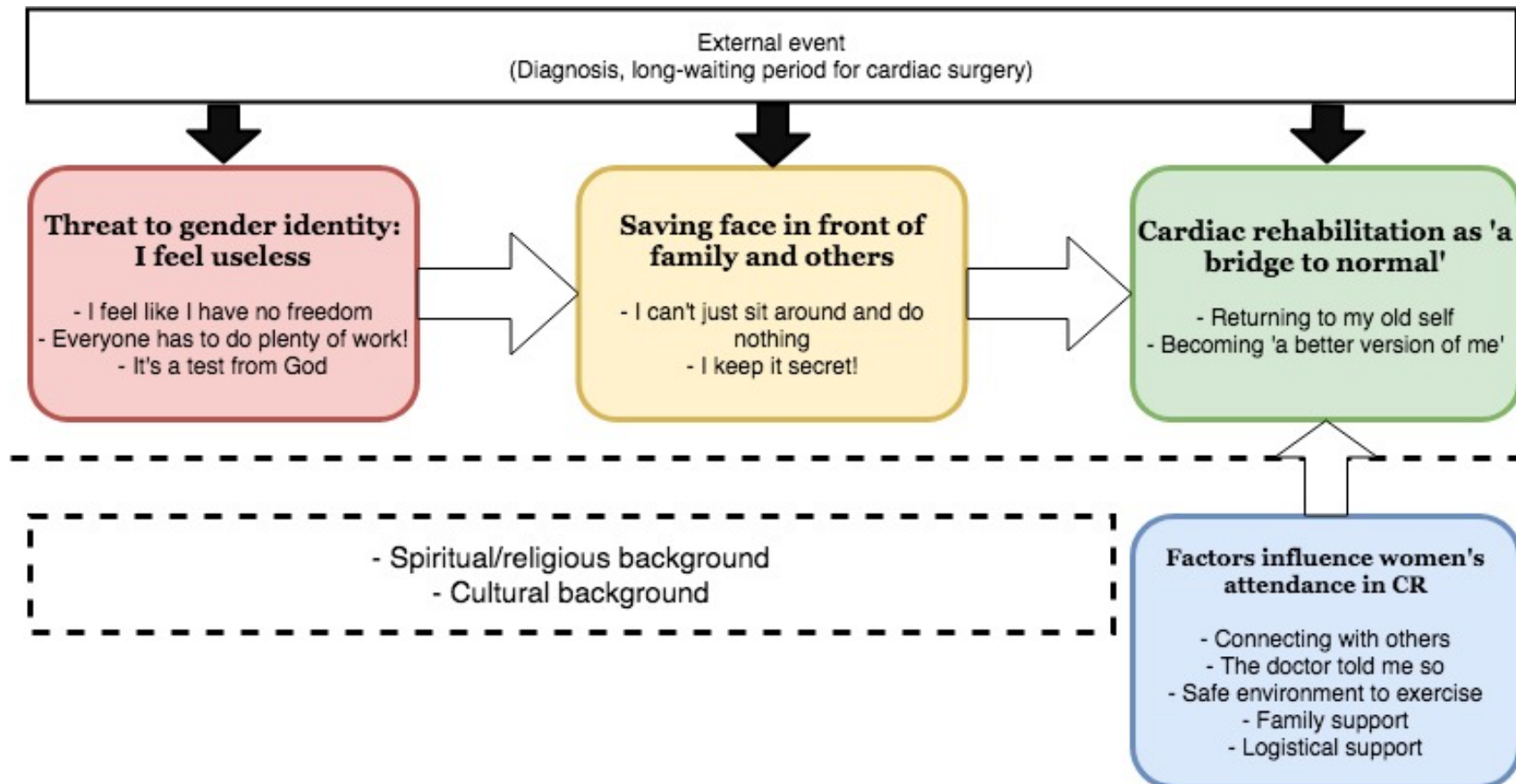


Figure 6.1 Overview of the study main findings

6.2 Intersection between culture, religion, and gender identity in shaping women's experiences

"Although few in Indonesia would claim to be feminists, it is legitimate to use the word to apply to much of the women's movement if we understand feminism in a basic sense as 'analysing the problem of women' and 'acting to oppose discrimination against women'."
(Blackburn, 2010, p. 22)

The quotation above accurately portrays my position in this study in adopting feminism to inform my thinking. As the focus of this PhD research is to investigate women's experiences with heart disease, feminism was utilised as a theoretical lens in this study. As highlighted in the earlier section, there is no distinctive method of doing feminist research. However, one goal that all feminists seem to have in common is the empowerment aspect and 'giving voice' to women (Ramazanoglu and Holland, 2002). I argued that the women who participated in this study experienced a form of empowerment following their attendance in the CR programme; a beneficial experience which was necessary for their recovery process. Moreover, by participating in this study, the women 'gave voice' to their narratives, and this 'voicing' also served as a form of empowerment. Through sharing information with other similar patients during their CR attendance, women were able to review their condition and life circumstances, gain knowledge and confidence, and develop the friendships that influenced them to make informed choices about their health. Specifically, their most significant choice was 'to continue their participation or to exit the CR programme.'

Due to the androcentric nature of research, women are often viewed as one large homogenous group (Reinharz and Davidman, 1992). However, the reality is the total opposite of that perspective, in which women's experiences are broad and diverse depending on their social location (i.e. cultural, economic, religious, etc.). In this research, I cannot claim that all the 26 women formed one large homogenous group or suggesting that their experiences of living with and recovering from heart disease were the same for all of them. What I am claiming is that although the women's experiences varied, all 26 women who participated in this study demonstrated, to varying degrees, what I call an alteration in their sense of self and particularly how their participation in CR was mediated by their goal of self-restoration. The process of self-restoration was contingent on role-related behaviours and expectations,

connections and relationships with others, and their perceptions of what they were enduring.

The study findings suggest that women's experiences of living with heart disease, and their decision to attend a phase two CR programme, were influenced by their gendered identities, Indonesian cultural context, and their religious beliefs. As mentioned earlier, the social construction of womanhood and role division between husband and wife in Indonesia has been strongly influenced by the blend of state ideology, cultural traditions, and religious values. It was found that the women in this research internalised cultural constructions of womanhood in Indonesia. As a result they are expected a) to perform the roles of a good mother and/or wife, b) to place the needs of others before their own, or c) to manage the household affairs. These obligations played a significant part in shaping their experiences of living with heart disease. This study showed how internalised norms and values, as well as expectations from others, shaped women's experiences with heart disease and subsequently influenced their decisions to attend CR programme. Despite their medical condition, the women in the current study continuously tried to fulfil what society expected of them. In this sense, attending a CR programme was part of the women's efforts to restore themselves physically and socially, as well as to prepare themselves to resume their previous roles and activities in the family and society.

It is evident that in an Indonesian context, religion and culture are intertwined with the lifestyle of the people; it would be difficult and possibly counterproductive to try to separate one from the other. This view is in line with the assertion from an Indonesian anthropologist (Koentjaraningrat, 1976), who stated that culture and religion are closely related to the daily life of the Indonesian people. Cultural and religious values are adopted into their life's discourses and relationships, as well as reflected through their attitudes, beliefs, thoughts, knowledge and experiences. According to Thompson et al. (1990) and Storey (2013), culture is the accumulation of knowledge, beliefs, art, morals, law, custom, hierarchies, values, meanings, religion, and other capabilities and habits acquired by individuals as members of society. The findings of this study revealed how women's understandings of cultural and religious beliefs, for instance in the construction of their roles and identities as a woman, impacted on their day-to-day experiences with heart disease, from the onset of the illness to the recovery period; particularly during their attendance in the CR programme.

Aligned with the social constructionist theories of 'self', self is both personal and socially constructed and developed through ongoing interactions, communication, language and social relationships (Gergen, 2011). My findings show that all the women in this study adopted the cultural expectations in which the roles of mother and/or wife were central to their identity. However, due to their heart disease they were unable to perform their roles based on Indonesian society's expectations or standards; an inability which in turn posed a major threat to their sense of self. Previous research suggested that gender role expectations play a significant role in shaping not only people's experience of illness but also their recovery. Despite the women's increased participation in the workforce and access to education, many women still have to carry dual roles within and outside the household (Angus, 2001). In addition to their occupational demands, they are expected to fulfil their caregiving responsibilities, such as housekeeping, looking after the children, or caring for ill family members. Finn (2001) argued that caregiving responsibilities negatively affect women's health and well-being, resulting in an excessive incidence of various chronic diseases in women.

Gender, religion, and cultural background colluded to produce different experiences for women with heart disease in Indonesia. Gender: a set of social expectations in relation to attributes and behaviour appropriate to women or men, is shaped by culture (Schalkwyk, 2000). For the Indonesians, it is widely known that women's roles as mother and wife are a central point of women's identities (Rosenberg, 2003). This widely accepted identity is particularly due to the influence of the Islamic religious prescriptions that regulate women's roles in Indonesia (Blackburn, 1999). The extensive literature on gender roles and power relationships between men and women within Islamic norms has focused more on the idea of what constitutes good women, good men, and good gender relations in both Indonesian and Islamic contexts (Qibtiyah, 2009).

Women are often situated as 'inferior to men' within cultural, religious, and political contexts in Indonesia. The social and cultural expectations placed on women's roles in the family context in Indonesia have not changed significantly over time. Women must continue to carry, and then manage, family responsibilities as their primary concern. Mulyani (2009) highlights that women in Indonesia have always been

socialised to think that men are the leaders and primary earner in the family. There is a well-known Indonesian proverb relating to women's roles in the family which states: *"wanita itu harus bisa mengurus dapur, sumur, dan kasur"* which means that a woman should be able to cook/prepare food for the family, to take care of the house, as well as to satisfy her husband sexually (Heraty, 2002, Sugihastuti et al., 2007). In addition, there is also a hadith (statement) from Prophet Muhammad about women's roles which is narrated by Abu Huraira: *"The righteous among the women of Quraish are those who are kind to the young ones and who look after their husband's property"* (Elias, 2010). However, there are various interpretations of this hadith. For some, this hadith has been understood to mean that the primary responsibilities of women are raising the children and taking care of the husband. If that were so, it would seem to limit, or even proscribe, a woman's opportunity to pursue higher education or a career. However, others believed that since women are to be responsible for raising children and managing the husband's property, thus women should be educated, trained, and supported to be able to perform their roles appropriately. In this current study, four women had pursued higher education and gained a university degree; half of the total participants were in the full-time or part-time employment. Therefore, the roles which have been adopted by the women in this study were more likely taken from contemporary social practices in an Indonesian context. Interestingly, whilst there has been an ongoing debate on women's roles in the family within Indonesian society, there are only limited debates or contradictory views with regards to men's roles in the family.

6.3 From a threat to a restoration of self

6.3.1 The concept of self: feminist perspective

Self has become one of the emergent themes in this study of women's experiences of heart disease and CR participation. Defining the concept of self is challenging as self is a complex, multifaceted phenomenon. There are many different theories related to the concept of self. Different approaches to the issues are demonstrated, depending on the philosophical background of those offering a definition. With regard to the traditional approach of self, the self is simply 'an innate and fixed entity'. As Crossley (2000) suggests

"The traditional approaches to the study of self are based on the assumption that the self exists as an entity that can be discovered and

described in much the same way as can any object in the natural or physical world.” (Crossley, 2000, p.9)

Feminist scholars argue that the process of defining the concept of self cannot be value-free. As Brison (1997) suggested:

“How one defines ‘self’ depends in part on what one wants the concept of self to do.” (p.14)

In line with the concept of feminist methodology, the concept of self within the feminist perspective is also varied and often controversial. Thus, there is no one grand unifying ‘feminist theory of self’. However, there are common themes within feminist literature concerning the self. Many feminist scholars have challenged the masculinisation of the self, as well as recognising the influence of both the sociocultural background, and the body, in the process of self-construction.

Feminist philosophers have argued that the traditional views and theories of self are androcentric and misogynist in that they define self as a free, rational, and autonomous agent (Meyers, 1997). For example, in Western culture, the mind and reason are associated with the masculine, whereas the body and emotions are viewed as feminine. Meyers (1997, p. 3) states:

“To identify the self with the rational mind is, then, to masculinise the self.”

In challenging the notion of the rational self, poststructuralists have been particularly vocal with the idea of the ‘core self’, arguing that the notion of the self, as an internally anchored entity that regulates and dictates who and what we are, is an illusion (Butler, 1990). The author maintains that the existing self-theories often ignore what she refers to as the *“performative nature of the self”* by creating and maintaining the illusion that one has a fixed and immutable self. Further, Butler (1990) claims that the whole idea of ‘woman’ is also illusory in a sense that there is no grand unifying concepts of woman’s essence or markers, and that self is as much created by socialisation as it is by one’s inherent self-perception. She characterises gender as being performative, of creating a presentation that is influenced by how one perceives oneself, and by how one internalises gendered messages throughout the culture. Also, she claims that gender is a complex mixture of socialised internalisations, including the

internalisation of social norms, physical shape, self-perception, as well as the presentation of particular gender identity. Other poststructuralists, such as Kristeva (1991), also argue against the single meaning of self, as well as questioning the notion of a single autonomous self.

6.3.2 Discussion

The study findings show that heart disease not only created functional limitations for the women patients but more importantly, had a significant impact on their sense of self. They perceived heart disease altered their daily lives and their feminine identity; specifically their internalised norms and perceptions about what it is to be an ideal woman in their context (Bird and Rieker, 1999). As this study has shown, since experiencing heart disease, the women were 'not able to do anything like before' in the sense of performing domestic duties, such as cleaning the house, cooking, nurturing the children, participating in social activities, or working outside the house. They felt that heart disease intertwined with, and altered the gendered expectations of, caring for others, which they perceived as central to their identity as a woman. At the same time, as cardiac patients, they were aware of the limitations imposed on them by the disease. Their very limited ability to carry out normal roles as a mother/wife meant they were no longer able to fulfil gendered expectations, mainly doing the household chores and caring for the family. This limitation caused the women to feel like a burden to their families, and thus threatened their sense of self. The feeling of being a burden to others contradicts the ideal characteristic of a 'good woman', as well as undermining the traditional feminine role of family caregiver in Indonesian society.

Norms could be described as the information around us, that comes from the broader social and cultural context, and define who we are subjectively, or as subjects. Norms guide our sense of what might define a person, offering a contrast between what is expected and what is outside of that. Butler (1990) asserts that social norm is an avenue by which cultural power is established and expressed, and these norms are carried out through social interactions and gendered behaviour. Frequently, norms are taken for granted expectations and understandings about how people act, behave and think. While one's gendered experience certainly involves reflection and direct agency, it is also the absorption of cultural narratives and norms (Butler, 1990).

The central assumption brought into this research, therefore, was that identity is developed through a woman's social and affective experiences and her behaviour in social interactions and settings. For this reason, my position is in line with the notion of 'performative nature of self' offered by Butler (1990). In this study, I believed that it is through social experiences and interactions, women learn how to act and behave according to the social norm in which they lived until such actions and behaviours become natural to them or a part of who they are. The women participants in this current study have always been taught to maintain independence and to fulfil their responsibilities, both within the household and within society. Additionally, they have construed themselves as a 'woman' in terms of being essentially the caretaker of the family, housekeeper, and a good wife/mother; the prescriptions of socio-cultural Indonesia. Hence, the occurrence of heart disease has caused what might be called a 'paradigm shift', in which the women who always saw themselves as independent, active, and strong has been transformed to where they saw themselves as a dependent, inactive, and weak. This 'paradigm shift' in turn, became a threat to their sense of self.

More than that, the diagnosis of heart disease has also caused uncertainty in the women's lives, particularly relating to the projection of their future and personal goals. These findings are similar to the findings of previous studies both in Western contexts (Kristofferzon et al., 2007, Pihl et al., 2011) and from an Asian perspective (Najafi Ghezeljeh et al., 2014). These studies suggested that patients with heart disease experienced changes in their physical abilities, roles, daily living, self-identity, and their views towards life. The inability to fulfil daily tasks causes people to suffer great emotional distress (Roebuck et al., 2001). Above all, the result of a meta-synthesis consisted of seven qualitative studies conducted in three different countries (Canada, Australia, and Sweden) suggests that women patients experience a greater sense of loss and frustration than do male patients, due to women's greater domestic roles in their normal situations (Hildingh et al., 2007).

The study findings show that the women, as a result of their heart problems, experienced threats to their identity. This is similar to the young males' experiences of MI in the UK (Merritt et al., 2017), which reported that the men also experienced a sense of losing 'manhood'. Their perceived loss resulted from their reduced physical

strength and capability, loss of independence, reduced financial power and loss, albeit temporary, of the main provider role in the family. These findings highlight the stereotypical gender roles and expectations in society, which placed men as strong, financially independent, and breadwinners. Therefore, it seems that social constructions of gender roles affect both men's and women's health in a similar way. The women in the current study were primarily concerned about losing their pre-illness roles in the family, particularly as a mother and a wife; whereas the men worried about losing the masculine attributes of being fit, strong, financially independent and a provider.

It was interesting to note that the younger participants, with relatively young children, were more concerned about their inability to look after others, such as their children, due to their illness-related physical limitations. For the older participants, especially those who lived with adult children, the social expectations were slightly different from those of the younger cohort. This difference is due to Indonesia culture, which obliges adult children to be responsible for taking care of their elderly parents. However, findings also showed that even the older women in this study (those above 60 years old) were still seriously concerned about not being able to take an active role in the family, such as looking after grandchildren, cleaning the house, or cooking for the family. Dalal and Biswas (2009) assert that being unable to provide support to family and friends can relatively quickly lead to an erosion of self-worth. According to Simon (2004), identity helps individuals to locate themselves in their social worlds, or helps them to anchor in their social worlds by giving them a sense of place. Therefore, most of the women in this study explained situations that related to a sense of social displacement, in which heart disease had prevented their full engagement in activities that were connected with their former identities. The respondents were concerned about losing standing in front of others who, it should be stressed were not ill. The woman's status would be lost, or significantly reduced, if they fail to live up to expectations for a person in a certain role or of a certain status. Loss can also occur as the result of not being able to perform their caring roles for others in the family.

A study in the UK into the impact of heart disease on relationships, showed that men also reported frustration at being a burden to their partners (Aldred et al., 2005). Specifically, men spoke of their reduced ability to fulfil their traditional roles as the breadwinner of the family, which they conceptualised as gender-specific. According

to Charmaz (1983), becoming a burden typically degrades identity because the ill persons have little power over their situations and the quality of their existences. Fear of being a burden has become a sustained theme in the literature of patients with life-limiting illness. A study that explored the experiences of men in Canada during recovery following a sudden cardiac arrest, noted that men also spoke of becoming burdens to others (Uren and Galdas, 2015). The male patients became more reliant on their partners for help with arranging and attending health care appointments, as well as looking after their medications. Interestingly, none of the men in the study addressed this as having an impact on their sense of independence or self-reliance. The men's willingness to accept support from their spouses/partners highlighted the traditional gender roles and expectations, in which women have been positioned as the family caregiver (Kristofferzon et al., 2003). This gender stereotype was also portrayed in a qualitative study by Hutton and Perkins (2008) who found that men in their study seemed to have a high expectation of support from their family. This observation is contrary to the findings of the current study, which have demonstrated how the women reported feeling uncomfortable about needing to rely on their family for support and assistance, whilst men expressed such family-based support to be important. However, Allison and Campbell (2009) suggested that the men in their study who were less than 60 years old were reluctant to discuss their illness experience with other people, even their spouses or partners. The men in their study tried to maintain their appearance of being stoical, invulnerable, and invincible. This finding suggests that the men have constructed their illness experiences around their masculinity.

Past and current research studies have explored how the self can change because of cardiac illness, as well as how the self can be both preserved and recovered following a cardiac event. King and Jensen (1994) and Fleury et al. (1995) explored women's recovery following cardiac surgery, as did more recent studies (Hildingh et al., 2007, Simoný et al., 2015, Dubbin et al., 2016). King and Jensen (1994) interviewed ten women after cardiac surgery to explore their experiences of recovery. Utilising a grounded theory approach, they reported that cardiac surgery had affected the women's sense of self, particularly in the aspect of social roles and changes in interpersonal relationship. King and Jensen (1994, p. 100) stated "cardiac surgery affected the very fibre of the women...: their sense of self." Therefore, the women in their study became involved in the process of self-preservation, while getting through their surgical experience. King and Jensen (1994) support other current feminist

literature that sees women's sense of self as not only related to her role, but related to connections and relationships she has to others. The women employed several strategies to cope with their situation and to maintain and preserve their sense of self, and move beyond their cardiac surgery experience. Although we employed different approaches of qualitative research, there are some similarities between King and Jensen's (1994) study and mine. The first similarity is in terms of participants; both studies were undertaken using women who had undergone cardiac surgery. Second, the women in their study and those in mine all struggled with the physical, psychological, and emotional effects of having a cardiac condition. Lastly, both the women that I studied and those in the King and Jensen study experienced a change in their sense of self as a result of a cardiac event.

6.4 Saving face as a strategy to preserve identity

Galick et al. (2015) argued that focus on the biomedical aspects of heart disease often led to the neglect of social and contextual aspects of patients' experiences by the healthcare providers. Following a significant loss of physical functions and social roles due to the illness, the participants sought to find a way to maintain their previous identity and status in the family and society. For this reason, women in this study implemented a number of strategies to mitigate disruptions in their daily lives. As has been mentioned above, saving face refers to the strategies that individuals use to cope with unpleasant situations, and particularly to eliminate any negative evaluations of self (Dong et al., 2013). Scarborough (1998) noted that saving face is also known as 'harmony-preserving' within the Chinese culture. By exercising these strategies, women hoped to be able to maintain their dignity in front of others.

Women in this study developed strategies to protect their social dignity and to maintain harmony within the family and society whilst also dealing with their current physical condition. In section 4.3, it has been explained that saving face is deeply rooted in Indonesian culture; a behaviour that was developed to preserve the individual's identity, as well as to protect the social order by ensuring conformity. For that reason, the women in this study employed complex strategies to balance their roles and their identities as a 'good mother', 'a good wife' and 'a sick person'. They were continuously re-negotiating and adjusting the assumptions and social constructs of good mothering, in order to facilitate both their mothering role and their sense of

self-esteem. Despite the diversity in the social and cultural backgrounds of the participants, gender norms and relationships were identified as a consistent theme in this study. Drawing on Butler's analysis, I am interested in the performative aspects of living with heart disease. In particular, Butler's (2000) approach illustrates something of how norms are created, maintained, and resisted.

Maintaining family harmony was noted as an important finding in this study. Confucianism, with its core concept of family harmony as a basis of a harmonious society, has had a strong influence on cultures and lifestyle in East Asian countries, including Indonesia (Pitaloka, 2014). For this reason, Indonesian society places a high value on social harmony; prescribing people to behave following certain rules and social conventions. The study findings demonstrated the continuous efforts of the women to maintain their roles as wife, mother, or grandmothers to protect their families from being overly worried about their condition, so that harmony in the family would be sustained. Many participants developed strategies that allowed them to balance their needs with the needs of others, to give them a sense of control over their daily activities. These findings have resonance with assertions from Sulik (2007) who identified the 'balancing act' as a vital coping strategy developed by women with breast cancer in the US. A 'balancing act' refers to:

"an attempt to establish an equilibrium between women's needs and the needs of others. The balancing act is both a process of resocialisation and a problem-focused strategy that, if successful, is capable of increasing women's sense of control in coping with the uncertainty of illness and engaging in care work for the self." (Sulik, 2007, p. 875)

Sulik (2007) also suggests the notion of "a good way to be sick", in which women identified what they are willing to do for themselves, as well as what they expect, ask for, and will accept from others. The current study findings illustrate how the ability to fulfil domestic roles and obligations as a mother and/or wife is central to the participants' understanding of living with heart disease. The participants explained that they sincerely accepted the illness but at the same time they did not want to abandon their obligations to the family and society. These findings have resonance with the assertion from Schou et al. (2008) who reported that the women in their study fought to maintain their role in their families as wives, mothers, or grandmothers. The emphasis that women in this study placed on their roles as wives and mothers also

concurs with Richardson's study (2005). It was noted that women presented themselves as a 'good housewife' despite their pain, in order to maintain a positive identity, reinforced by continuing to perform their traditional gender roles (Richardson, 2005). Williams and Koocher (1998, p. 329) describe this type of coping behaviour as being "*in charge of the illness rather than being controlled by the disease process*".

My study findings suggest that women were reluctant to continually ask for help because they did not like to feel dependent on others, nor did they wish to be a burden on their family. The concern of the patients regarding this matter clearly illustrates that, for them, having a sense of control over daily activities and family obligations was essential. Although performing household tasks aggravated their health condition, the women stated that it also helped to improve their sense of usefulness in the family. The definition of control offered by Pearlin et al. (1981, p. 340) also has relevance here; control is "*the extent to which people see themselves as being in control of the forces that importantly affect their lives.*" This is similar to the research by Baker et al. (2016) who reported that 'upholding previous routines was an important aspect for participants in their attempt to maintain normality or continuity from the past'. In this case, the traditional feminine role as housekeeper acts as a strategy to maintain and bolster their self-esteem and self-worth. Helpard and Meagher-Stewart (1998) suggested that housekeeping activities help women to cope with illness, as well as giving them both identity and self-esteem. The researchers also reported that in certain circumstances, women try to over-engage in certain household chores as a means of coping with disruptions to their former roles. Similarly, the findings of qualitative studies conducted among Swedish women (Svedlund et al., 2001, Burström et al., 2012) also reported that despite their lack of physical capacity to perform the household tasks, the women post AMI and CHF in Sweden tried to keep up appearances and hide their fatigue, so that they would not be judged as lazy.

The study findings also showed the women's efforts to maintain harmonious relations among family members by restraining and controlling their own emotional responses, for instance by not complaining, or getting angry easily over little things. This conscious attempt was aimed to protect their identities as 'a good woman' intact. According to Brenner (1998), a woman who grew up in a Javanese family, they have been taught how to "live in concern for others" (*prihatin*), how to make sacrifices, and to exert vigorous efforts to achieve desired outcomes. In addition, the Javanese

concept of social interaction has been built on two fundamental values: peace (*damai*) and harmonious integration (*rukun*). Peace and harmony are the ideal conditions that everyone should strive for, in which there are “no intense feelings of resentment, or at least [they] are not expressed...look for compromise solutions...to minimise conflict within the family” (Geertz, 1989, p. 149-151). This attitude is in line with the women’s experience in a patriarchal society in Pakistan, as reported by Barolia et al. (2017). The researchers found that in order to maintain family harmony and to prevent arguments, women who had very recently experienced a cardiac event, chose to obey their husband in terms of food choices and preparation. They were concerned with their husband’s anticipated aggressive behaviour if they did not serve the food that they wanted. A previous study conducted in Australia by DiGiacomo et al. (2011) found that despite fatigue, women with CVD continuously prioritised the needs of their family before their own. Therefore, the women often missed CR sessions due to their caregiving activities or the concomitant effects of their physical or emotional exhaustion.

The findings showed that participants preferred to hide their illness from those they did not want to disclose to, particularly from outsiders. This is similar to the findings of a study among Punjabi Sikh participants living in the UK (Sidhu et al., 2016). It was reported that keeping emotional distress inside the family system seemed to be important for the participants, in order to avoid social stigma. By revealing the illness or the internal conflict in the family, the participants can no longer protect their dignity in front of others. Bedford and Hwang (2003) asserted that the exposure of one’s failures or flaws will lead to the experiencing of shame. This prediction chimes with the findings of Bhattacharyya et al. (2016), who studied Indian and Bangladeshi patients following their cardiac events. The participants in their study reported that they chose to conceal their illness from their work colleagues in an attempt to preserve their pre-sickness identity. One of the women in our study concealed her heart problems from her family out of fear of being a burden and source of stress for others. This concurs with other research in Western contexts, which reported women deliberately hid their illness, particularly if the symptoms interfered with household duties and caring for others (Currie and Wiesenbergh, 2003) or if they assumed they would become a burden to their family (Davidson et al., 2008, Medved and Brockmeier, 2011).

The participants in my study adopted various strategies to cope with their suffering. Apart from their illness, the women consciously and unconsciously, attempted to always sustain the image of a strong woman, showing positive characteristics of self-reliance, independence, and being responsible for their daily activities; all such efforts focused on avoiding being judged as 'lazy'. These findings suggest the need to acknowledge the connection between the physical aspect of self and mental aspects; a relationship that involves identity, and sociocultural contexts in shaping the respondents' experiences with heart disease.

6.5 Attending CR: a bridge to restore women's sense of self

Day (2003) found that social factors strongly influenced women's experience of a heart attack from the onset of symptoms through to the recovery and rehabilitation process. When the women found their abilities, independence, and self-reliance diminished by the effects of the cardiac event, they looked for assistance and ways to retain a measure of control and function. The findings in my research show that all the women in this study, saw the phase two CR programme as one-step in their cardiac journey, pointing the way to recover their physical and psychological health and to move forward with their lives. Women in this study who had already learned, accepted, and adapted to their new condition showed resilience and determination about regaining their health after the acute cardiac event. In this respect, the participants regarded their engagement in the phase two CR programme as a "bridge" to get back to normal, which in turn will lead to a self-restoration. Attending CR also gave participants the opportunity to confront their lives and to actively change those aspects of it that had been affected by their heart disease.

Fleury et al. (1995) conducted a qualitative study to describe women's recovery after an acute cardiac event. Data was collected from 13 women through a group format via group meetings. It was found that 'building a bridge' was an important step in a woman's recovery process, following an acute cardiac event. The role of self in the recovery process was further explored in a later study by Fleury et al. (2001), who stated that:

“The self system is increasingly being recognised as an important antecedent or correlate for understanding health behaviours. Recovery from any major life event involves both physiologic and psychosocial stress, which requires acknowledgement analysis and attention to self.” (p. 72)

Fleury (2001) also concurred that the physiological and psychological effects of a cardiac event significantly impact upon the self and that the self is significantly important during the healing process from a cardiac event:

“Indeed the self guides the process of meaning making, which contributes to the understanding of the experiences of illness and functions to stabilise the self.” (Fleury et al., 2001, p. 72)

It was evident that the roles of a mother and a wife were central to the participants' identity in my study. However, suffering from the consequences of heart disease that was marked by changing images of the self, posed a threat to the women's identity, as they were no longer able to maintain their required and expected roles as a mother and a wife. For these reasons, the findings showed that the motivation for women's attendance in the phase two CR programme, was to restore themselves physically, psychologically, and socially. In this sense, the restoration of self was the ultimate motive for the women attending the phase two CR programme in Indonesia.

The women in this study identified two distinct meanings of self-restoration: 1) to return to their old selves, and 2) to become a 'better version of me'. First, to be restored means to return to their old, as in former, selves so that the women would be able to resume their previous roles and responsibilities in the family and society. They felt uncomfortable with attempts made by their children or husband to provide assistance in what they saw as 'their' domestic roles. Often they expressed the opinion that it would be extremely difficult for them to return to their homes without resuming their previous roles. The findings show that by attending CR, the women were able to see a possible path to recovery, through regaining their strength, improving their appetite, or just generally striving to 'feel better'. Corbin and Strauss (1988) described recovery as the resumption of activities of daily living and the return to an independent role after an illness. The participants believed that the programme could facilitate them to 'return to normal' by regaining their physical health, which in turn will restore their social standing in front of family and others; the beginning of a

positive cycle. This perspective complements the work of Simoný et al. (2015), which demonstrated that CR helped Danish men and women to overcome uncertainty and guided them to find new values in life. This view is also supported by other studies that indicated that CR helped to overcome the almost inevitable presence of anxiety and uncertainty following a cardiac incident (Dechaine and Merighi, 2017, Rouleau et al., 2018). In a study conducted by Uren and Galdas (2015) male subjects reported that CR helped them to build up their confidence, which in turn assisted their recovery.

Second, self-restoration is also considered as an improvement from the past in which the participants described themselves as having been changed by the cardiac event in a positive light. Illness can cause a significant disruption of a person's life, while at the same time also allows them to choose a life that they want to lead, as opposed to living out the one they had accumulated over the years (Frank, 1991). The participants agreed that their cardiac disease adversely affected them physically and mentally; thus, they expressed that it would be hard to return to a similar level of activity as before. From their narratives, the experience of living with heart disease had resulted in a permanent change to their sense of who they are, and how they wanted to be. Therefore, many participants also emphasised their flexibility and capacity to grow following their recent cardiac event. The findings are consistent with the results of the studies by (Holder et al., 2015, Astin et al., 2014), which indicates that cardiac events at some point also prompted individuals to experience positive, life-transforming changes during their recovery. The findings of this study propose that during the recovery period following a cardiac event, women incorporated the potential for personal growth and change. The experiences made the women recognise new aspects of themselves, especially relating to their personal strength and resilience. Fleury (1995) noted:

“Attempting to grow through uncertainty in healing facilitated the initiation and maintenance of health behaviour change by allowing women a needed focus on self and openness to changing roles; the opportunity to explore possibilities in individual goals and plans to attain valued goals; a reinforcement of inner strength in managing personal and environmental barrier, and the re-evaluation of intrapersonal and environmental in caring for and nurturing self.” (p. 481)

Some participants described how their recent cardiac events prompted them to live in the present and not to worry about their future life. Women emphasised the importance of flexibility in responding to individual and situational demands. This point is similar to a recent study of participants who survived multiple rib fractures (Claydon et al. (2017). The researchers reported that the traumatic event had prompted the individuals to reflect on their life experiences and led to a change in participants' attitudes to life and their futures. However, participants with an acute cardiac event in the study by Bhattacharyya et al. (2016), particularly those Bangladeshi participants who were of working age and low socioeconomic class, felt pessimistic about their future life due to their financial concerns. However, different more positive attitudes were expressed by the participants who attended higher education and had a skilled non-manual job; presumably, at least in part, because they did not have any chronic or pressing financial problems.

The findings demonstrate that following their cardiac event the women started to reform their personal goals and redefine their priorities, working out what was important for them. In terms of physical exercise, many participants stated that they learned many things from the CR programme. They predicted they had every intention of adopting an exercise plan once they return home. The life-altering experiences, of both heart disease and cardiac surgery, had caused the women to change their priorities in life. Positive changes following traumatic events have long been widely recognised in the literature as post-traumatic growth (Linley and Joseph, 2004). More specifically, such growth may relate to issues such as; a) the concept of self, b) relationships with others, c) life philosophies, and d) behavioural patterns (Calhoun and Tedeschi, 2014). Linley and Joseph (2004) suggested there is evidence that women experience higher levels of post-traumatic growth, than do men.

The findings of this study concur with the findings of the study by Angus et al. (2018). The researchers suggest that the overall CR goals were not the primary consideration of patient's attendance in the CR programme. Instead, their primary concern was to restore their social dignity within other spheres, including family, employment, and society in general, that has been affected by their CVD diagnosis. This research, therefore, adds to previous knowledge that there is a connection between the past, the present, and the future in relation to women's decisions to attend a phase two cardiac rehabilitation programme (Bäck et al., 2017). The significant impact heart

disease had on women's capacity to perform their normal day-to-day activities encouraged the women to focus on taking care of themselves. This focus was motivated by their attempts to return to their roles, responsibilities, and usual 'work'. It should be noted that in this example 'work' for the women is not only about employment outside the home, but also involves 'labour' associated with household duties and caregiving responsibilities.

Also, Angus et al. (2018) make the point that gender is not the primary axis of difficulty for CR participation, due to the similarities of the accounts of their illnesses and rehabilitation from both men and women. The researchers further suggest that considerable negotiation, cooperation, and improvisation across social fields, would be meaningful and useful in order to increase the uptake and completion of the CR programme. In this respect, attending the phase two CR programme was not just to 'get better'; it was also part of the women's tactics to reclaim their previous social position and roles in both family and society. The participants greatly valued and appreciated the social connections with, and support from, the other patients in the CR programme. Also valued highly was support from the CR professionals in the way they monitored the safety of patients when doing their exercise activities. The patients were also unanimous in their appreciation of, and in some cases a little surprised at, the support received from family and friends.

Medved and Brockmeier (2011), in their study on men and women's experiences following a cardiac incident, reported that women felt more isolated as compared to men in their experience of heart disease. The cardiac illness, and the subsequent hospitalisation, posed a disruptive threat to many of the connections which the women in this study held dear, whether involving husbands, children, other family members, or friends. Maintaining old and developing new relationships in light of serious illness was challenging for some of the women, at least initially. Findings in this study demonstrated that meeting and interacting with other patients in the CR centre was seen as the most crucial beneficial aspect of the phase two CR programme. New contacts, new friends and plenty of 'me-too' advice from fellow patients gave the women participants from this study a sense of comfort and reassurance. Specifically, the CR's social dimensions helped the participants and patients in general to gain confidence during their recovery period. Davidson et al. (2008) identified the relationships between women patients as equal and non-hierarchical, which is in

contrast to their experience in the medical provider-patient relationship. Making friendships was a significant phenomenon that was considered by participants as empowering; it served to facilitate the process of self-restoration. The formation of feminine (women-to-women) friendships, and the friendship itself, can assist the re-creation and restoration of the feminine self. Miller (1976) as cited in Benenson (2014, p. 243) stated that:

“women stay with, build on, and develop in a context of connections with others. Indeed, women’s sense of self becomes very much organised around being able to make and then to maintain affiliations and relationships. Eventually, for many women the threat of disruption of connections is perceived not as just a loss of relationship but as something closer to a total loss of self.”

The feelings of being less of a burden, and having the opportunity to help others with similar conditions, helped the women to gain or regain a sense of normalcy into their lives. In this sense, the phase two CR programme experience builds a bridge where the women developed mutual relationships, as well as a forum where they can share their concerns and experiences. As Fleury et al. (1995) highlighted, it is through the support group that: *“women began to abdicate the role of primary caretaker in their relationships, to enter as a partner in relationships that supported their personal growth and changing worldview”* (p. 480). By interacting with other patients, women feel less of a burden since they actively involved in a give-and-take emotional process; particularly when they have the opportunity to provide encouragement and support for others (Galick et al., 2015). Research suggests that while men expected practical support and advice, women greatly value the social and emotional support the programme provides, as well as its other aspects (Neubeck et al., 2012, Clark et al., 2013).

The roles women take in relation to others, because of gender socialisation, influence how they approach and prioritise their own health (Galick et al., 2015). Much research suggests the woman’s social roles associated with childcare, housework, and family life to be barriers preventing women’s participation in a CR programme (Caldwell et al., 2005, Davidson et al., 2008, Gallagher et al., 2008, Tod et al., 2002, Clark et al., 2013, Day and Batten, 2006). However, the majority of the women in this study, regardless of their familial and societal obligations, still managed to complete the phase two CR programme. These findings are in line with the findings of King and Jensen (1994) and Fleury et al. (2001) who explored the self, and its role in healing,

often define self as a multifaceted phenomenon. A woman with a feminine self can, whilst being influenced by others, autonomously narrate and subjectively reflect upon her own life experiences, and can work with others to maintain and if necessary restore the self.

The collectivist culture in Indonesia gave an advantage to the women in this study as they could get support from families or friends easily, in terms of being helping with the issue of caring for their children or housework while they were away on the CR programme. Support from family became a significant factor that led to women's participation and completion in the CR programme. Traywick and Schoenberg (2008) identified that conflicting demands and lack of social support were the main barriers to exercise among older women who had survived a heart attack in the US. Moreover, as women typically considered themselves as the anchor of the family, following the surgery, women in my study found it difficult to imagine themselves not being able to take their former roles when they returned home. For this reason, they preferred to complete their CR programme first so that they would be able to protect their social dignity; they made sure that when they got home they would not be seen as a 'weak' person. The findings show that the women who appeared to be caring for themselves seemed to take a conscious stance to put themselves first. In contrast to women, men assumed that their family members are responsible for their health-promoting behaviour following a cardiac event (Medved and Brockmeier, 2011).

The influence of the women's social environment on women's attendance in the CR programme was evident. Family and friends' support provided strength to the women in this study concerning their participation in the phase two CR programme. However, Galick et al. (2015) reminded healthcare providers not to assume the presence of a family network is synonymous with family support. Being surrounded by family members, or having spouses or partners, does not necessarily guarantee that women receive the kind of support that they need (Knudson-Martin, 2009).

With respect to socioeconomic status, all women in this study had access to some level of medical care, diagnostic procedures, and health insurance. This factor has been identified as an essential facilitator for their attendance in the phase two CR programme. Only one participant reported she did not have insurance to cover the CR programme; thus, she was unable to attend and so dropped out. Qualitative

research conducted by Pedersen et al. (2017) identified the inhibiting issue of 'exclusion', when patients perceived that they did not fit into the framework of CR, and hence 'exclusion' can be another barrier preventing CR participation.

Consistent with the extensive literature on CR participation, many of the female patients in the current study also reported that they decided to take the rehabilitation programme mainly because of the recommendation from their physician. Recommendation from a doctor has been identified as a critical factor positively influencing CR participation (Ades et al., 1992). The findings of the current study are congruent with other studies which identified that a written referral, complemented by a strong recommendation and educational material about the importance of CR, facilitates participation in a CR programme (Clark et al., 2013, Neubeck et al., 2012). Hence, according to Dankner et al. (2015), lack of knowledge regarding the benefits of CR hindered patients from participating in a CR programme. In a qualitative study by Banerjee et al. (2010), who interviewed 16 South Asian participants in Canada, it was revealed that the participants' biggest motivation to attend CR was the safety aspect of the CR programme. To perform exercise under qualified professional supervision in a safe environment provided the participants with an appreciated feeling of reassurance.

In this research, women's motivation to embark on 'restoring self', combined with the availability of instrumental, informational, and emotional or affective aspects of support from healthcare providers, friends, and families, were revealed as the reasons behind the successful completion of the phase two CR programme. The findings suggest that under some circumstances women would attend and complete CR programme as a way to restore themselves to normal. Although restoring gender identity and roles was one of the most significant factors informing the women's attendance in CR, there are other multiple and interconnected considerations and factors that influence each woman's decision to attend and complete the CR programme; or not to do so. Each determinant alone is not enough to encourage women to participate in the CR programme. For this reason, in an attempt to improve the participation rates among women in phase two CR programmes, gender-focused interventions and CR programmes should be designed to address those multiple influences simultaneously.

6.6 Chapter summary

The research findings confirmed the findings available in the literature which state that CR attendance is multifactorial. For the women in this study, suffering from the consequences of heart disease on their day-to-day life has facilitated their decision to attend a hospital-based, professionally supervised phase two CR programme. The findings of this study also revealed that women's decisions to attend a CR programme were mainly influenced by their expectation and desire to restore themselves physically, mentally and socially, so that they would once again be able to resume their roles in the family and community. I consider that the whole process of attending CR as well as self-restoration involves elements of empowerment. It can be seen that the opportunity to share information and experiences with other patients, the formation of friendship, or discussion with healthcare professionals have increased women's knowledge and confidence; hence it has positively affected the women and empowered them to make informed choice about their health, such as continued attendance at CR, or adopting a healthy lifestyle.

CHAPTER 7: Conclusion

7.1 Introduction

In this final chapter, I present the limitations of this PhD study and recommendations that can be drawn from this research. Further, I explore some of the implications and recommendations for practice, policy and future research arising from this investigation.

7.2 Limitations of the study

Despite a certain amount of knowledge having been produced from this study, in relation to women's experiences of heart disease and their attendance in a CR programme, I recognise there are several limitations need to be considered.

I identified the main limitations of this study related to the research site, the study sample, and the data collection method. With regards to the research field, this study was conducted in only one CR centre in Indonesia. While the National Cardiovascular Centre Harapan Kita in Jakarta served patients from across Indonesia, a total of one research site might be viewed as a limitation as the location of the CR centre does not necessarily represent other CR services in Indonesia. This factor potentially limits the transferability of the study findings to other settings (Lincoln and Guba, 1985). Therefore, I am aware that the evidence from this study may not reflect a larger Indonesian or international perspective. The findings would only reflect the experiences of Indonesian women being treated in Java. Although the 26 women I interviewed in this study came from a diverse cultural and ethnic background, their experiences still cannot be considered as representative of all women in Indonesia, so generalising my findings is not possible. However, due to the limited number of hospitals that offer CR services in Indonesia, all of which are located in big cities, I consider this research site to be the most appropriate location for this study.

Second, with regards to the study sample, this research only focused on female participants who enrolled in the CR programme. Although initially, I planned to include both the attenders as well as the non-attenders, this research only involved the women who attended CR. Among the 26 women who participated in this study, 21 of

them completed the CR programme, while 5 of them dropped out before completion. Attempts have already been made to recruit participants who did not attend CR, as outlined in chapter 3, but this recruitment was not possible. In addition, all the women in this study had undergone cardiac surgery; non-cardiac surgery patients were ineligible for this particular CR programme. Therefore, the women in this study were in a serious medical and physical condition, which may have influenced both their illness experiences and subsequent decisions to attend the CR programme.

Another limitation is related to the data collection method in this study. I utilised interviews as the primary method for generating data in this study, so it was possible that the participants would give answers to me, the interviewer, which did not reflect their real situation; equally they might provide answers designed to leave a positive impression. Being aware of this possibility, I adopted the approach of prolonged-engagement, as well as developing a non-hierarchical relationship with the participants, described in chapter 3. In addition, whenever appropriate I used probing questions during the interviews to obtain deeper insight from the participants.

7.3 Implications and Recommendations

The following recommendations are made based on the findings of the present study. These recommendations focus on strategies to improve women's participation in the CR programme. In addition, recommendations for future research are also presented.

7.3.1 Implications and recommendations for practice

While many similar topics have been the focus of research in a Western context, no previous study was found that focused on understanding the experiences of women with heart disease in Indonesia. Thus, the current guidelines for heart disease management in the country still rely on evidence from Western contexts; advice which apparently fails to take women's experiences into account. The findings in this study suggest recognising their cultural and spiritual values, where heart disease is perceived as a test from the God, or a challenge to the importance of maintaining family and social harmony, is vital for the participants to manage heart disease in their day-to-day lives. For this reason, CR nurses or other healthcare professionals should have intercultural competence skills, so they would be able to deliver services that meet the social, spiritual, and cultural needs of their patients. Healthcare

professionals should be aware of the ethnic and cultural backgrounds of the patients so they would be able to determine the different behaviour of the patients with CVD. In addition, when giving lifestyle recommendations to the women, a sociocultural context within which patients are encouraged to make behavioural changes needs to be considered.

Findings from this study portray women's multiple roles and identities that they carry with them at all times, and how heart disease affected their ability to perform these roles in their everyday lives. It was found that restoring self was the primary goal of women's attendance in the CR programme in Indonesia. In discussing the meaning of self-restoration, women were not only concerned with their physical recovery, but they were also very concerned about restoring their social dignity within other spheres, including family, employment, and society in general that has been affected by heart disease. Moreover, participants also described two distinct meaning of self-restoration. While many participants described the importance of being able to return to their old selves, many participants also emphasised their flexibility and capacity to grow following their recent cardiac event.

Some participants described how their recent cardiac events prompted them to live in the present and not to worry about their future life. The women also started to reform their personal goals and redefine their priorities, working out what was important for them. The findings of this study propose that during the recovery period following a cardiac event, women incorporated the potential for personal growth and change. The study findings, therefore, emphasise the need for the development of a personalised care plan within the area of CR, so that the CR programme would be more suitable to the need of each woman. One-by-one approach that has already initiated in the hospital to inform the patients about the CR programme could be optimised by involving the patients and their family in the formulation of goals of their recovery and CR programme. Healthcare practitioners need to listen to what is essential to the individuals – their preferences, hopes and concerns, and their ideas for what might work, in discussion with family and friends if they choose. Using a partnership approach, healthcare practitioners and the patients can together formulate goals and action plans for their cardiac rehabilitation that focus on what would help the patients to improve their lives over the next few weeks, month or a year. Future work to

increase CR attendance in Indonesia, therefore, should be both gender- and culturally-sensitive to the needs of the female CVD patients.

Since this study focused on exploring what makes women participate in the CR programme, the findings from this study highlight several factors that influence women's attendance in CR. These identified factors are: a) early enrolment, b) recommendation and endorsement from physicians, c) adequate family support, d) support from other CR participants, e) individualised programme, f) a non-competitive environment, g) supportive staff, and h) availability of financial support. Future CR programmes need to address and consider these multiple aspects to promote women's participation in the CR programmes. The findings of this study suggest that endorsement and recommendation from a physician or other health care providers, was a vital aspect of the women's initial engagement in the CR programme. Therefore, one of the moves to improve women's uptake of the CR programme should be directed towards efforts to promote initial engagement by the women, such as by ensuring that all patients receive invitations to attend the programme. Furthermore, systematic approaches, such as an automated referral system or liaison/nurse-to-patient contact, together with early enrolment, should be used as standard practice to improve participation in CR.

Social support from family or spouse was found to be essential to facilitate women's recovery from heart disease. Findings showed that social support from family members and friends played an important role throughout their journey with their cardiac illness; support started at the point of diagnosis, through cardiac surgery, up until completion of the CR programme. The women described that they received a great deal of support from their family and friends, input which gave them the strength to deal with their conditions. For this reason, the inclusion of the family and close friends in the planning of women's care should be considered in any initiatives designed to improve the uptake of CR. Family involvement is vital for the management of cardiovascular disease among women. In order to be able to provide support as well as to take an active part in the women's recovery and rehabilitation, healthcare professionals should equip the family, significant other, or both with adequate information about heart disease, as well as ways to promote their health, and how to provide support for them.

The study also highlights social connections and relationships with other patients in the CR programme as being one of the most critical factors that facilitate women's attendance in a phase two CR programme. Furthermore, the women in this research valued the supportive and friendly CR staff, as well as the individualised exercise programme, which gave them the confidence to perform the CR exercises. It is reasonable to suggest that the CR programme should continue to encourage good communication between the patients and CR staff as well as with other patients. Development of women's support groups in CR would probably be beneficial in facilitating women's participation. Therefore, the findings of this study can assist healthcare professionals to better understand the needs of women and the fit between women's needs and existing CR programme, thereby providing direction for more effective approaches to CR programme.

7.3.2 Implications and recommendations for further research

My study has highlighted areas that are appropriate for further investigation and I present these here as recommendations for future research studies. First, since the commencement of this particular project, it has proved to be particularly difficult to find literature on CR programmes in Indonesia. For this reason, there would appear to be a need to assess and evaluate the existing CR clinical guidelines, programmes, and strategies in Indonesia; with a view to mapping the future directions and plans for CR implementation countrywide. Secondly, since this study only focused on the investigation of women's attendance in the CR programme, their experiences may differ significantly from those who were not attending and thus, not enrolled for interview. Future research should be directed at investigating the reasons for women's non-participation in or dropping out from the CR programme in Indonesia.

The findings from this study also raised several questions related to the broader issue of men's experiences of heart disease and their attendance in the CR programme. Future research should be directed to explore men's attendance in CR programmes, particularly within the Indonesian setting. Several issues could be addressed such as i) how heart disease affects men's day-to-day lives and ii) how men cope with heart disease. Moreover, future research could also be conducted to compare men's and women's experiences, to investigate how gender interplays with ethnic or religious backgrounds and how masculinity and femininity influence their illness experiences. An important finding from my study was the importance of social, cultural, and spiritual

values to the women's experiences with heart disease. Further research could be directed to investigate how cultural and spiritual values affect women's recovery rates from heart disease. In addition, a comparative study of the experiences of patients with heart disease in Western and Asian settings could be conducted.

7.3.3 Implications and recommendations for policy

The 'evidence-policy gap' has been extensively discussed in the health literature. There are several challenges in translating research evidence to influence or change policy, such as lack of time, resources, and support for researchers to engage in disseminations. Equally it is likely that many policymakers may lack the competence to understand the scientific evidence. Nevertheless, Cairney and Oliver (2017) noted two key problems identified in the literature: 1) studies rarely draw on policy theory or the knowledge of the policy process, and 2) studies rarely recognise the role of values in politics. Hence, the authors suggested that scientists should understand the tendency of policymakers to make quick decisions based on their emotions and familiarity of and with the information. For these reasons, to be effective the act of persuasion should combine both scientific evidence and emotional appeal. Furthermore, they assert that a successful engagement between evidence and policymaking requires pragmatism (Cairney and Oliver, 2017).

In an effort to combat the growing cardiovascular epidemic, as well as to improve cardiovascular care, in Indonesia, through ministerial decree No. 854/Menkes/SK/IX/2009, the government has operationalised several initiatives, including: i) empowering communities to control the risk factors of CVD, ii) reducing the delays in help-seeking by increasing the access to early detection services, iii) training primary care workers and family practitioners to assess and manage cardiovascular risk, and iv) increasing the financing allocated to controlling the risk factors of CVD (MoH, 2009). However, very little is known about the real needs of cardiovascular care in Indonesia; in particular how or if the strategies set out by the government in meeting those needs are in any way effective. As has been discussed in section 1.4.4, Indonesia is still struggling with an undersupplied and unevenly distributed healthcare system lacking both personnel and facilities for dealing adequately with CVD. Maharani and Tampubolon (2014) provide empirical evidence of the failure of the Indonesian government in meeting the population's needs for competent cardiovascular care. In their research, it was revealed that only one-third

of their survey respondents with cardiovascular risk received adequate cardiovascular care. Individuals who i) have low socioeconomic status (SES), ii) live in rural areas, and iii) have no health insurance, have a lower probability of receiving cardiovascular care services, including cardiac rehabilitation, than the rest of the nation's population.

The findings of this study show that women were willing to participate in a phase two CR programme. However, it was found that the distance from location of the CR programme's delivery, caused some of the women in this study to drop out of the programme. Additionally, it was found that the insurance coverage for CR only covered the patients with surgical interventions, hence potentially can be problematic for the post-MI patients, who have not undergone any surgical intervention, to access the programme. The implications of these findings can be used to inform the policy makers to develop policies that change CR practice and delivery.

Change could be achieved by improving access to CR programmes for the patients, by providing the population with an effective health insurance scheme, as well as using alternative delivery models for CR such as CR programmes offered in the local hospitals or primary care clinics. Other options could involve the use of home-based or community-based CR, or smart-phone based CR. These innovative methods suggest a promising approach to improving CR participation levels among women, as they offer a flexibility that suits women's needs. I suggest that further research is still required to explore the viability of these CR access initiatives in Indonesia. However, the recent health policy (BPJS Director Regulation No. 2, 3, and 5, 2018) clashes with the recommendations set out in the present study, as well as with the previous health policy, that aim to improve access to cardiovascular care services. Rather than extending the health insurance scheme, the government issued a new regulation concerning CR, stating that health insurance will only cover a maximum of two CR sessions a week. Therefore, based on this new regulation, if patients attend a CR programme more than twice a week they will be required to make out-of-pocket payments. This regulation highlights the issue of the 'evidence-policy gap' that persists in Indonesia. Consequently, the efforts to improve patients' participation in CR programme would be even more challenging in the future, as those initiatives would appear destined to fail without adequate support from the policy makers.

The findings presented in this study have also demonstrated that “role related functions and identities” play an important role in determining when and under what conditions women choose to seek medical help, particularly in making a decision to enrol on a CR programme. Nonetheless, the current policies and regulations in Indonesia are still in the form of a gender-neutral health policy. Therefore, the study’s findings should persuade policy makers to move away from a gender-neutral approach to focus their attention on developing gender-sensitive health policies. Perhaps, just as importantly, those policies need to be culturally-sensitive in the area of CVD prevention and rehabilitation, so as to increase the acceptability and suitability of the programme for a wider population in Indonesia. Further, the study findings provide an additional source of empirical support in informing future health policies which aim to design CR programmes that are both gender and culturally-sensitive to the needs of Indonesia’s female CVD patients.

7.4 Chapter Summary

There is a scarcity of research that explores women’s participation in the CR programme in Indonesia. This current study has attempted to gain an understanding of women’s experiences of heart disease and their participation in phase two CR programme in Indonesia by conducting a feminist-informed qualitative research initiative.

This thesis has highlighted the importance of the women’s cultural and spiritual backgrounds in shaping the way they perceive their gender roles, in the context of suffering from heart disease. To my knowledge this is the first study in an Indonesian setting to consider women’s experiences of living with heart disease, as well as attending a post-operative phase two CR programme. Contrary to the findings from previous studies that identified fatalistic beliefs as a barrier for help-seeking behaviour, this study found that religious beliefs have been transformed into sources of empowerment to tackle their condition and to seek help. The research findings have revealed that role-related functions were essential for the women in defining themselves. The women’s motivation to attend their CR programme was mainly driven by their expectations to be able to resume their previous roles in the family, society, and employment. Consistent with the extensive literature on women’s CR participation, the factors which influenced women’s attendance in CR that were revealed in this study are multifactorial. The factors were: i) referral and endorsement

from a physician, ii) emotional, moral and social support from other patients, iii) support from family, iv) safety aspects of the CR programme's presentation and location, and v) logistical factors.

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Appendices

Appendix 1 Searching strategy

CINAHL (1984 - 2018)					
Code	Keywords	Results	Code	Combination	Results
A1	women	316,259	B1	A1 or A2	1,649,315
A2	female	1,588,032	B2	A3 or A4 or A5	45,402
A3	cardiac rehabilitation	6,047	B3	A6 or A7 or A8 or A9	159,431
A4	exercise based	21,343	B4	A10 or A11 or A12 or A13	150,030
A5	secondary prevention	19,234	C1	B1 and B2 and B3 and B4	399
A6	cardiovascular disease	87,830		(full text and abstract available, english language)	227
A7	myocardial infarction	48,387			
A8	heart disease	45,734			
A9	heart attack	49,357			
A10	participation	74,145			
A11	involvement	53,825			
A12	engagement	22,849			
A13	attendance	10,480			

MEDLINE (1946 - 2018)					
Code	Keywords	Results	Code	Combination	Results
A1	women	785,604	B1	A1 or A2	8,032,511
A2	female	7,995,617	B2	A3 or A4 or A5	35,283
A3	cardiac rehabilitation	5,354	B3	A6 or A7 or A8 or A9	420,788
A4	exercise based	780	B4	A10 or A11 or A12 or A13	548,283
A5	secondary prevention	29,932	C1	B1 and B2 and B3 and B4	389
A6	cardiovascular disease	96,103		(full text and abstract available, english language)	129
A7	myocardial infarction	21,041			
A8	heart disease	147,504			
A9	heart attack	3,543			
A10	participation	143,749			
A11	involvement	366,189			
A12	engagement	38,156			
A13	attendance	19,207			

PsycINFO (1997 - 2018)					
Code	Keywords	Results	Code	Combination	Results
A1	women	253,904	B1	A1 or A2	462,925
A2	female	264,967	B2	A3 or A4 or A5	3,348
A3	cardiac rehabilitation	834	B3	A6 or A7 or A8 or A9	20,835
A4	exercise based	260	B4	A10 or A11 or A12 or A13	249,471
A5	secondary prevention	2,252	C1	B1 and B2 and B3 and B4	37
A6	cardiovascular disease	8,846			
A7	myocardial infarction	4,060			
A8	heart disease	9,500			
A9	heart attack	866			
A10	participation	95,672			
A11	involvement	103,845			
A12	engagement	57,655			
A13	attendance	18,037			

EMBASE (1980 - 2018)					
Code	Keywords	Results	Code	Combination	Results
A1	women	1,144,417	B1	A1 or A2	8,455,750
A2	female	8,331,175	B2	A3 or A4 or A5	44,598
A3	cardiac rehabilitation	8,948	B3	A6 or A7 or A8 or A9	832,882
A4	exercise based	1,519	B4	A10 or A11 or A12 or A13	768,799
A5	secondary prevention	35,767	C1	B1 and B2 and B3 and B4	681
A6	cardiovascular disease	315,690		(Limit full text and abstract and english language)	197
A7	myocardial infarction	249,012			
A8	heart disease	356,666			
A9	heart attack	5,653			
A10	participation	180,645			
A11	involvement	522,833			
A12	engagement	61,602			
A13	attendance	31,106			

Appendix 2 Ethical Approval from the University of Edinburgh



NURS017

Tantri Sutantri
Nursing Studies
School of Health in Social Science
Medical School
Teviot Place
Edinburgh
EH8 9AG

SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Doorway 6
Medical Quad
Teviot Place
Edinburgh
EH8 9AG

26 May 2016

E-mail: Susanne.Kean@ed.ac.uk Tel: 0131 651 1983
E-mail: Sarah.Rhynas@ed.ac.uk Tel: 0131 650 3882
Fax: 0131 650 3891

Dear Tantri

APPLICATION FOR LEVEL 3 APPROVAL

PROJECT TITLE: GENDER-BASED ANALYSIS OF INDONESIAN WOMEN'S PARTICIPATION IN CARDIAC REHABILITATION PROGRAMMES

Thank you for submitting the above research project for review by the Section of Nursing Studies Ethics Research Panel.

I can confirm that the submission has been independently reviewed and was approved on 26 May 2016.

Should there be any change to the research protocol, it is important that you alert us to this as this may necessitate further review.

Yours sincerely

Susanne Kean
Researcher/Lecturer
Nursing Studies

Sarah J Rhynas
Teaching Fellow
Nursing Studies

Appendix 3 Ethical Approval from Hospital



KEMENTERIAN KESEHATAN
DIREKTORAT JENDERAL PELAYANAN KESEHATAN
RUMAH SAKIT JANTUNG DAN PEMBULUH DARAH HARAPAN KITA

Jalan Let. Jend. S. Parman Kav. 87 Slipi Jakarta 11420
Telpon 021.5684085 – 093, 5681111, Faksimile 5684230
Surat Elektronik : info@pnhk.go.id
<http://www.pnhk.go.id>



Nomor : LB.02.01/II/0059../2016
Hal : Izin Penelitian

17 Juni 2016

Yang terhormat,
Ketua Program Studi Ilmu Keperawatan
Fakultas Kedokteran dan Ilmu Kesehatan
Universitas Muhammadiyah Yogyakarta
Jalan Lingkar Selatan, Tamantirto, Kasihan, Bantul
Yogyakarta 55183

Sehubungan surat Saudara Nomor 136/D.2-VIII/PSIK/IV/2016 tanggal 8 April 2016 Hal Ijin Penelitian, Surat Persetujuan Etik (*Ethical Approval*) dari Ketua Komite Etik Penelitian Nomor LB.02.01/VII/102/KEP.0025/2016 tanggal 7 Juni 2016 dan Surat Ketua Komite Etik Penelitian Nomor LB.01.02/VII/103/KEP.025/2016 tanggal 10 Juni 2016 Hal Hasil Telaah Etik Protokol Penelitian dengan judul "**Studi Kualitatif tentang Partisipasi Perempuan dalam Program Rehabilitasi Jantung Fase II di Rumah Sakit Jantung dan Pembuluh Darah Harapan Kita**", atas nama :

Peneliti Utama : Sutantri, S.Kep.,Ns.,M.Sc
Institusi : Fakultas Kedokteran dan Ilmu Kesehatan, Universitas Muhammadiyah Yogyakarta.

Kami dapat menyetujui permohonan tersebut, dengan ketentuan :

- 1 Membayar biaya penelitian sesuai tarif yang berlaku (Tarif terlampir);
- 2 Membawa Surat Tugas yang dibuat oleh Fakultas Kedokteran dan Ilmu Kesehatan, Universitas Muhammadiyah Yogyakarta;
- 3 Untuk informasi lebih lanjut dapat menghubungi Sekretariat Divisi Penelitian dan Pengembangan (Ibu Retnani Prihatin/ Ibu Kartika) Telp. (021) 5684085-93 ext. 2831/32.
- 4 Hasil/data yang diperoleh 1 (satu) berkas agar diserahkan ke Divisi Litbang Rumah Sakit Jantung dan Pembuluh Darah Harapan Kita;

Atas perhatian dan kerjasama Saudara diucapkan terima kasih.



Dr. dr. Hananto Andriantoro, Sp.JP(K), MARS, FICA
NIP. 195711041986101001

Tembusan:

1. Ka. Divisi Penelitian dan Pengembangan RSJPD. Harapan Kita;
2. Ka Instalasi Prevensi dan Rehabilitasi Kardiovaskular RSJPD Harapan Kita;
3. Ka Instalasi Rekam Medik RSJPD Harapan Kita.

Appendix 4 Participant Information Sheet



PARTICIPANT INFORMATION SHEET

SCHOOL OF HEALTH IN SOCIAL
SCIENCE

The University of Edinburgh
Medical School
Doorway 6 Teviot Place
Edinburgh EH8 9AG

Project title:

Indonesian women's participation in cardiac rehabilitation programmes

Introduction

I am Sutantri, a doctoral candidate in Nursing at the University of Edinburgh, United Kingdom. I am doing a research on the women's participation in cardiac rehabilitation programmes in Indonesia. This research is part of the requirement of my Doctoral Degree in Nursing Studies. I would like to invite you to take part in this research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part.

What is the purpose of the study?

Cardiac Rehabilitation (CR) has been proven to be effective in improving the quality of life for people with or at high risk of heart disease. The main purpose of this study is to explore the factors that influence women's attendance in cardiac rehabilitation programme.

Why have I been invited?

You are being invited to participate in this research because you are a woman between the ages of 30-99, just had a recent experience of heart attack, and living within one hour of the hospital. We feel that your experience can contribute much to our understanding and knowledge of the reasons for women's attendance in cardiac rehabilitation programme.

Do I have to take part?

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this Centre will continue and nothing will change. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you accept to take part in this research, you will be asked to participate in an interview lasting around an hour with myself. The interview will mainly explore your experience and perception about CR programme. During the interview, I will sit down with you in a comfortable place at the cardiac rehabilitation centre in the National Cardiovascular Centre, Harapan Kita Hospital. If it is better for you, the interview can take place in your home or other location at a date and time of your choosing. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but myself as the interviewer will be present unless you would like someone else to be there.

Expenses and payments?

Your participation in this study is voluntary, so you will not be provided any incentive to take part in the research.

What are the possible disadvantages and risks of taking part?

We do not anticipate any risks. However, we are going to ask you to share with us some very personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you do not wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. If the interview upsets you and you feel you would like some additional help after the interview I will be able to advise you to contact the cardiology nurse (X) or the counsellor (X) in this hospital.

What are the possible benefits of taking part?

There will be no direct benefit to you, but your participation is likely to help us to understand the conditions that influence women's participation in cardiac rehabilitation programmes. The findings of this study may provide a foundation to design the most appropriate cardiac rehabilitation programmes that suit the women's needs in the future.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. No one else except me and my thesis supervisors will access to the information documented during your interview. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. The entire interview will be digitally-recorded, transcribed onto a computer, and the voice file will be destroyed. Anyone who takes part in this research will be identified only by code number or false name. Only the researchers will know what your number is and we will lock that information up with a lock and key. You can be assured that if you take part in this study you will remain anonymous.

What will happen if I don't carry on with the study?

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your cardiac rehabilitation process in any way. You may stop participating in the interview at any time that you wish without your cardiac rehabilitation programme being affected.

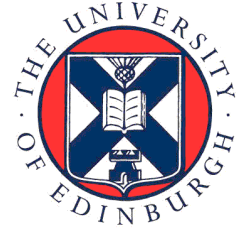
What will happen to the results of the research study?

The knowledge that we get from this research will be shared with you and the healthcare staff in the National Cardiovascular Centre, Harapan Kita before it is made widely available to the public. There will be small seminar or presentation at the cardiac rehabilitation centre and it will be announced. Our findings will also be published in peer-reviewed journals and presented at relevant conferences. Although we may directly quote your words, you will not be identifiable from those words in any publications.

Further information and contact details:

If you have any further questions or you need additional information about this research, please contact: Sutantri, telephone (+44) [REDACTED], email address: [REDACTED]. Alternatively, you can speak to my supervisors Dr. Fiona Cuthill (email: [REDACTED]) or Dr. Aisha Holloway (email: [REDACTED]).

Appendix 5 Participant Information Sheet in Bahasa Indonesia



LEMBAR INFORMASI PARTISIPAN

School of Health in Social Science

The University of Edinburgh

Medical School

Doorway 6, Teviot Place

Edinburgh EH8 9AG

Judul

Partisipasi Perempuan dalam Program Rehabilitasi Jantung Fase II

Pendahuluan

Perkenalkan, saya Sutantri, dosen di Universitas Muhammadiyah Yogyakarta dan juga merupakan mahasiswa S3 Keperawatan di University of Edinburgh, Inggris. Saya sedang melakukan penelitian tentang keikutsertaan perempuan dalam program rehabilitasi Jantung di Pusat Jantung Nasional, Harapan Kita. Penelitian ini merupakan salah satu persyaratan untuk mendapatkan gelar Doktor Keperawatan. Saya ingin mengundang Anda untuk berpartisipasi dalam penelitian ini. Sebelum Anda memutuskan untuk berpartisipasi atau tidak, saya ingin menjelaskan tentang segala sesuatu yang berkaitan dengan penelitian ini serta sejauh mana keterlibatan Anda di dalam penelitian yang sedang dijalankan ini. Mohon untuk menyediakan waktu untuk membaca lembar informasi ini secara cermat. Jika ada sesuatu yang kurang jelas, atau Anda membutuhkan tambahan informasi silakan untuk bertanya kepada saya.

Apakah tujuan penelitian ini?

Rehabilitasi Jantung telah terbukti efektif untuk meningkatkan kualitas hidup pasien dengan atau berisiko tinggi mengalami penyakit jantung. Tujuan utama dari penelitian ini adalah untuk mengetahui alasan perempuan untuk berpartisipasi dalam program rehabilitasi jantung.

Kenapa saya diminta untuk ikut berpartisipasi?

Anda diundang untuk berpartisipasi dalam penelitian ini karena Anda memenuhi kriteria partisipan kami, diantaranya: wanita, berusia di atas 30 tahun dan baru saja menjalani rawat inap karena serangan jantung. Kami merasa bahwa dengan pengalaman Anda, Anda dapat memberikan kontribusi yang sangat berarti untuk kami dalam memahami dan mengetahui tentang alasan dari keikutsertaan wanita dalam program rehabilitasi jantung.

Apakah saya harus ikut penelitian ini?

Keikutsertaan Anda dalam penelitian ini sepenuhnya sukarela. Pilihan untuk ikut atau tidak ikut andil dalam penelitian ini ada di tangan Anda. Jika Anda memilih untuk tidak berpartisipasi, semua pelayanan di rumah sakit ini akan tetap sama dan tidak akan berubah. Selain itu, jika Anda memutuskan untuk ikut dan tiba-tiba berubah pikiran, Anda bisa mengundurkan diri kapan saja tanpa harus menceritakan alasan Anda serta tanpa dikenai denda atau pun sanksi apapun.

Apa yang akan terjadi jika saya ikut penelitian ini?

Jika Anda menyatakan untuk ikut berpartisipasi dalam penelitian ini, Anda akan diminta untuk berpartisipasi dalam dua sesi wawancara dengan diri saya sendiri selama kurang lebih satu jam. Wawancara ini terutama akan menanyakan tentang pengalaman dan persepsi Anda mengenai program rehabilitasi jantung. Selama wawancara, saya akan duduk bersama Anda di suatu tempat yang nyaman di pusat rehabilitasi jantung

Harapan Kita. Akan tetapi, Anda juga bisa memilih untuk melakukan wawancara di rumah Anda atau tempat lain yang Anda rasa lebih nyaman kapan pun Anda mempunyai waktu luang. Jika ada pertanyaan selama wawancara yang membuat Anda merasa tidak nyaman, Anda bisa mengatakannya kepada saya dan kita bisa melanjutkan ke pertanyaan selanjutnya. Tidak ada orang lain, selain diri saya sendiri akan hadir saat proses wawancara kecuali atas permintaan Anda.

Apakah saya akan mendapat insentif?

Kami akan memberikan souvenir sebagai bentuk ucapan terimakasih atas partisipasi Anda.

Apakah ada kerugian atau resiko jika saya ikut dalam penelitian ini?

Kami tidak mengharapkan akan terjadinya resiko apapun. Namun, kami akan meminta Anda untuk menceritakan beberapa informasi pribadi, dan jika Anda merasa tidak nyaman membicarakan hal-hal tertentu, Anda tidak perlu menjawab pertanyaan tersebut atau ikut dalam wawancara. Anda tidak perlu memberikan alasan apapun kepada kami ketika Anda tidak berkenan menjawab pertanyaan tertentu, atau menolak di wawancara. Jika selama proses wawancara membuat Anda merasa marah atau sedih dan Anda membutuhkan seseorang untuk berbicara setelah wawancara, saya merekomendasikan Anda untuk berbicara dengan perawat (X) di pusat rehabilitasi ini.

Apakah keuntungan mengikuti penelitian ini bagi saya?

Mungkin tidak ada keuntungan secara langsung yang akan Anda rasakan sekarang, tetapi keikutsertaan Anda banyak membantu kami untuk memahami kondisi-kondisi yang mempengaruhi partisipasi wanita dalam program rehabilitasi jantung. Hasil penelitian ini akan menjadi landasan untuk merancang program rehabilitasi jantung yang sesuai dengan kebutuhan wanita di masa mendatang.

Bagaimana dengan kerahasiaan?

Semua informasi yang kami kumpulkan dari Anda selama penelitian ini akan secara ketat kami jaga kerahasiaannya. Tidak ada orang lain selain saya dan dua dosen pembimbing saya yang akan melihat informasi apa saja yang kami kumpulkan selama wawancara. Kami tidak akan menyebarkan informasi yang kami dapat selama wawancara ke luar tim penelitian. Semua informasi dari wawancara akan kami rekam dalam sebuah recorder, akan kami salin ke dalam computer, dan suara rekaman langsung akan kami hapus. Kami juga akan mengganti nama asli Anda dengan nama inisial, sehingga kerahasiaan data Anda akan terjamin.

Bagaimana jika saya tidak bisa mengikuti proses penelitian sampai selesai?

Anda tidak perlu ikut penelitian ini jika Anda tidak berkenan untuk melakukannya, dan memilih untuk tidak ikut serta tidak akan berimbas terhadap proses perawatan dan pengobatan Anda..

Apa yang akan terjadi dengan hasil penelitian ini?

Hasil penelitian ini akan kami sampaikan kepada Anda dan tenaga kesehatan di PJN Harapan Kita. Kami akan melakukan presentasi atau seminar di PJNHarapan Kita (untuk waktunya akan disampaikan kemudian). Selain itu, hasil penelitian ini juga akan dipublikasikan di jurnal internasional dan dipresentasikan dalam seminar yang sesuai. Walaupun kita mengutip sebagian kata-kata Anda saat wawancara, tetapi nama Anda akan disamarkan sehingga kerahasiaan Anda tetap terjamin.

Informasi lebih lanjut

Jika Anda memiliki pertanyaan atau membutuhkan tambahan informasi tentang penelitian ini, mohon untuk menghubungi diri saya sendiri: Sutantri, nomor telepon [REDACTED] alamat email: [REDACTED] Selain itu, Anda bisa berbicara dengan pembimbing saya Dr. Fiona Cuthill (email: [REDACTED]) or Dr. Aisha Holloway (email: [REDACTED]) Anda juga dapat menanyakan tentang penelitian ini kepada Komite Etik Penelitian RS Jantung dan Pembuluh Darah Harapan Kita, Telp [REDACTED] ext. [REDACTED] atau email: [REDACTED]

Appendix 6 Informed Consent Form



SCHOOL of HEALTH IN SOCIAL
SCIENCE

The University of Edinburgh
Medical School
Doorway 6 Teviot Place
Edinburgh EH8 9AG

By signing below, I confirm that:

1. I have read and understood the information about the project, as provided in the Participant Information Sheet ☐
2. I have been given the opportunity to ask questions about the project and my participation. ☐
3. I voluntarily agree to participate in this project ☐
4. I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn. ☐
5. The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me. ☐

Participant:

Name of Participant Signature Date

Researcher:

Name of Researcher Signature Date

Appendix 7 Letter of Invitation



SCHOOL of HEALTH IN SOCIAL
SCIENCE

The University of Edinburgh
Medical School
Doorway 6 Teviot Place
Edinburgh EH8 9AG

Date

Dear _____ (Participant's name),

My name is Sutantri. I am a doctoral candidate in the Nursing Studies Department at the University of Edinburgh. I am conducting a research study as part of the requirements of my degree in Nursing, and I would like to invite you to participate in this research study.

Currently, I am studying the reasons of women's participation in cardiac rehabilitation programme. If you decide to participate in this study, you will be asked to participate in an interview lasting around an hour with myself. The interview will take place at cardiac rehabilitation centre, a mutually agreed upon time and place.

I have included a detailed information sheet about the study with this letter. Please take time to read this.

I will be very happy to answer any questions you have about this study. You may contact me at (+44) [REDACTED] and [REDACTED] if you have study related questions or problems. If you need any additional information you may also contact my supervisors Dr. Fiona Cuthill (email: [REDACTED]) or Dr. Aisha Holloway (email: [REDACTED]).

If you are interested to take part in this study, I will telephone you in the very near future to discuss the study in more detail and to arrange a meeting for interview. Thank you for your consideration.

Yours sincerely,

Sutantri

Appendix 8 Letter of Invitation in Bahasa Indonesia

Kepada Yth.
Bapak/Ibu/Sdr/I
Di Tempat

Perkenalkan, saya Sutantri, dosen di Universitas Muhammadiyah Yogyakarta dan juga merupakan mahasiswa S3 Keperawatan di University of Edinburgh, Inggris. Saya sedang melakukan penelitian tentang keikutsertaan perempuan dalam program rehabilitasi Jantung di Pusat Jantung Nasional, Harapan Kita. Tujuan utama dari penelitian ini adalah untuk mengetahui alasan perempuan untuk berpartisipasi atau tidak berpartisipasi dalam program rehabilitasi jantung.

Pemilihan partisipan dalam penelitian ini didasarkan pada pengalaman yang Anda miliki saat dan setelah mengalami serangan jantung. Apabila Anda memutuskan untuk tidak terlibat dalam penelitian ini, maka Anda boleh mengundurkan diri dari penelitian kapan pun.

Penelitian ini tidak membahayakan dan tidak akan menimbulkan kerugian bagi partisipan. Peneliti akan menggunakan wawancara semi-terstruktur untuk mengeksplorasi pengalaman dan persepsi Anda mengenai program rehabilitasi jantung. Wawancara akan dilakukan selama dua sesi dan tiap sesi berlangsung selama 45 – 60 menit dan selama wawancara berlangsung akan dilakukan perekaman. Segala bentuk biaya yang dikeluarkan partisipan terkait dengan penelitian akan diganti dan terdapat *souvenir* untuk partisipan penelitian.

Hasil dari penelitian ini akan bermanfaat sebagai landasan untuk merancang program rehabilitasi jantung yang sesuai dengan kebutuhan wanita di masa mendatang di Indonesia. Peneliti akan menjaga kerahasiaan data yang diperoleh, identitas partisipan tidak akan dicantumkan oleh peneliti (menggunakan koding) baik dalam pelaporan maupun publikasi. Data yang didapatkan akan disimpan dengan pengamanan dan akses terbatas hanya untuk peneliti. Hasil dari penelitian ini akan diberikan kepada RSJPD Harapan Kita, instansi pemerintahan dan atau organisasi profesi terkait sebagai bahan rujukan untuk pengembangan program rehabilitasi jantung. Penelitian ini akan dipresentasikan dalam seminar dan dipublikasikan di jurnal ilmiah.

Informasi lebih lengkap mengenai penelitian ini dapat Anda baca dalam Lembar Informasi Partisipan. Jika Anda memiliki pertanyaan atau membutuhkan tambahan informasi tentang penelitian ini, mohon untuk menghubungi diri saya sendiri: Sutantri, nomor telepon [REDACTED] alamat email: [REDACTED]. Bapak/Ibu/Saudara juga dapat menanyakan tentang penelitian ini kepada Komite Etik Penelitian RS Jantung dan Pembuluh Darah Harapan Kita, Telp [REDACTED], ext. [REDACTED] atau email: [REDACTED]

Jakarta, Mei 2016
Peneliti

Appendix 9 Informed consent in Bahasa Indonesia

LEMBAR PERSETUJUAN PENELITIAN

Saya yang bertanda tangan di bawah ini menyatakan telah mendapatkan penjelasan penelitian tentang **Studi Kualitatif tentang Partisipasi Perempuan dalam Program Rehabilitasi Jantung Fase II di RSJPD Harapan Kita**. Saya memahami pelaksanaan penelitian dan tujuan penelitian yang akan berdampak terhadap pengembangan program rehabilitasi jantung.

Saya mengetahui dengan sadar bahwa tidak ada risiko yang saya alami dengan ikut menjadi partisipan dalam penelitian dan saya telah mendapat informasi tentang jaminan kerahasiaan informasi yang saya berikan. Saya menyatakan bersedia menjadi partisipan dalam penelitian: **Studi Kualitatif tentang Partisipasi Perempuan dalam Program Rehabilitasi Jantung Fase II di RSJPD Harapan Kita**.

Jakarta,2016
Peneliti,

Partisipan,

Sutantri

.....

Appendix 10 Leaflet for participants' recruitment in Bahasa Indonesia

TERIMAKASIH ATAS
PARTISIPASI ANDA

UNDANGAN BERPARTISIPASI



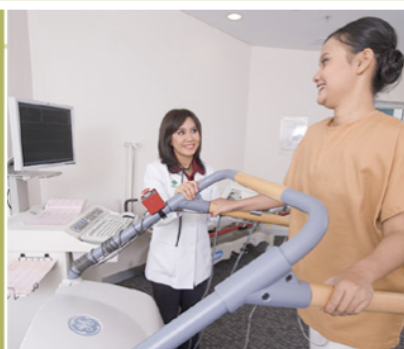
Studi Kualitatif tentang Partisipasi Perempuan
dalam Program Rehabilitasi Jantung Fase II

INFORMASI LEBIH LANJUT

Jika Anda tertarik untuk berpartisipasi dalam penelitian ini dan memiliki pertanyaan atau membutuhkan tambahan informasi, mohon untuk menghubungi saya: **Sutantri**, nomor telepon **081225778655**, alamat email: **ns.tantri@gmail.com**.

Selain itu, Anda bisa berbicara dengan pembimbing saya Dr. Fiona Cuthill (email: **Fiona.Cuthill@ed.ac.uk**) or Dr. Aisha Holloway (email: **Aisha.Holloway@ed.ac.uk**)

Anda juga dapat menanyakan tentang penelitian ini kepada Komite Etik Penelitian RS Jantung dan Pembuluh Darah Harapan Kita, Telp 5681111, ext. 2837/2831 atau email: **rb.kometik_rsjpdhk@gmail.com**



RUMAH SAKIT JANTUNG DAN PEMBULUH DARAH HARAPAN KITA

Jl. Letjen S. Parman, Kav. 87, Slipi, Jakarta Barat, 11420

Sutantri
PhD Student in Nursing Studies
The University of Edinburgh

Siapa yang mengadakan penelitian ini?

Penelitian ini dilaksanakan oleh Sutantri yang merupakan dosen di Universitas Muhammadiyah Yogyakarta dan juga merupakan mahasiswa S3 Keperawatan di University of Edinburgh, Inggris. Penelitian ini merupakan salah satu persyaratan untuk mendapatkan gelar Doktor Keperawatan di bawah supervisi Dr. Fiona Cuthill dan Dr. Aisha Holloway di University of Edinburgh.

Apa yang akan terjadi jika saya ikut penelitian ini?

Jika Anda menyatakan untuk ikut berpartisipasi dalam penelitian ini, Anda akan diminta untuk berpartisipasi dalam dua sesi wawancara dengan diri saya sendiri selama kurang lebih satu jam. Wawancara akan dilakukan di pusat rehabilitasi jantung Harapan Kita, ataupun di rumah Anda atau tempat lain yang Anda rasa lebih nyaman.

Apakah tujuan penelitian ini?

Rehabilitasi Jantung telah terbukti efektif untuk meningkatkan kualitas hidup pasien dengan atau berisiko tinggi mengalami penyakit jantung. Tujuan utama dari penelitian ini adalah untuk mengetahui alasan perempuan untuk berpartisipasi atau tidak berpartisipasi dalam program rehabilitasi jantung.

Apakah keuntungan dan kerugian mengikuti penelitian ini bagi saya?

Mungkin tidak ada keuntungan secara langsung yang akan Anda rasakan sekarang, tetapi keikutsertaan Anda banyak membantu kami untuk memahami kondisi-kondisi yang mempengaruhi partisipasi wanita dalam program rehabilitasi jantung. Hasil penelitian ini akan menjadi landasan untuk merancang program rehabilitasi jantung yang sesuai dengan kebutuhan wanita di masa mendatang.

Kenapa saya diminta untuk ikut berpartisipasi dalam penelitian ini?

Anda diundang untuk berpartisipasi dalam penelitian ini karena Anda memenuhi kriteria partisipasi kami, diantaranya: wanita, berusia di atas 30 tahun dan baru saja menjalani rawat inap karena serangan jantung.

Bagaimana dengan kerahasiaan?

- Semua informasi yang kami kumpulkan dari Anda selama penelitian ini akan secara ketat kami jaga kerahasiaannya.
- Tidak ada orang lain selain saya dan dua dosen pembimbing saya yang akan melihat informasi apa saja yang kami kumpulkan selama wawancara.
- Kami juga akan mengganti nama asli Anda dengan nama inisial, sehingga kerahasiaan data Anda akan terjamin.



Apakah saya harus ikut penelitian ini?

Keikutsertaan Anda dalam penelitian ini sepenuhnya sukarela. Jika Anda memilih untuk tidak berpartisipasi, semua pelayanan di rumah sakit ini akan tetap sama dan tidak akan berubah. Selain itu, jika Anda memutuskan untuk ikut dan tiba-tiba berubah pikiran, Anda bisa mengundurkan diri kapan saja tanpa harus menceritakan alasan Anda serta tanpa dikenai denda atau pun sanksi apapun.

Appendix 11 Pictures in research field



Appendix 12 In-depth interview guide

INTERVIEW GUIDE

Hello, my name is Tantri. Currently, I am doing a research on women's participation in cardiac rehabilitation programmes. During the interview, I would like to explore about your experience and perception about cardiac rehabilitation programme as well as barriers and facilitators to participate in this programme.

I would like to remind you that whatever we discuss today will be confidential and will only be used for this research project. Also your name will not be used, to make sure that no one can identify you with any answer. In addition, this discussion would be recorded, thus we don't miss anything that you said. Before we start, I would like to ask you to sign this consent form to indicate that you have agreed to participate in this interview and to be recorded. Do you have any questions before we begin?

Background information

Can you tell me a bit about yourself?

Probe: Age, education background, occupation, ethnicity

Can you tell me about the people you live with?

Lead Questions

Can you start by telling me what happened with you when you had been admitted to the hospital? Probe: When it was happened? What diagnosis did you receive at the hospital?

When did you first experience it? What did you know about your disease?

Could you describe the events that led up to your admission to the hospital?

What was going on in your life after knowing that you suffered from heart disease?

What positive changes have occurred in your life since experiencing heart disease?

What negative changes have occurred in your life since experiencing heart disease?

Could you describe a typical day for me before and after you were diagnosed with heart disease? Probes: what about your roles in family or society in general?

Tell me about how you describe the person you are now?

Where do you see yourself in two years' time?

What helps you to cope with your condition?

Who is most helpful to you so far and why?

Could you tell me who is the most important person in your life and why?

What have you learned/are you learning through this experience?

How have you changed as a person since experiencing heart disease? (Probes: what is your priority now?)

Attendance in cardiac rehabilitation

What did you know about cardiac rehabilitation programme? (Probes with: what is the advantages and disadvantages of CR programme?)

Could you tell me what was your motivation of attending the CR programme?

How did you decide to attend CR programme? Probes: when did you decide? What factors that lead to your decision to attend or not to attend? What about the support from family or friends? What types of support you find most useful during the decision-making process? What did you expect from this programme?

What has been changed since you attending this CR programme?

Could you tell me of the barriers of attending the programme (if any) and how you cope with it?

What advice would you give to someone who is about to begin cardiac rehabilitation?

Closing question

We are now reaching the end of the discussion. Is there anything else you want to add or discuss?

Appendix 13 In-depth interview guide in Bahasa Indonesia

PANDUAN WAWANCARA

Selamat siang ibu, perkenalkan saya Tantri, saya sedang melakukan penelitian tentang partisipasi pasien dalam program rehabilitasi jantung di rumah sakit Harapan Kita. Selama kurang lebih satu jam ke depan saya ingin berbincang-bincang dengan ibu terkait pengalaman dan persepsi ibu terhadap program rehabilitasi jantung.

Apapun yang kita diskusikan hari ini, akan saya jaga kerahasiaannya. Saya ingin meminta ijin ibu untuk merekam pembicaraan kita siang ini. Baiklah, sebelum kita mulai saya ingin meminta ibu untuk menandatangani lembar persetujuan ini. Apakah ada yang ingin ibu tanyakan sebelum kita mulai?

Background info:

- Ibu, bolehkah ibu ceritakan tentang ibu dan keluarga ibu?
 - o Berapa usia ibu saat ini? Asli nya mana? Lahir dan besar dimana?
 - o Dulu ibu bersekolah dimana?
 - o Apakah ibu saat ini masih bekerja? Di bidang apa?
- 1. Bisakah Ibu ceritakan apa keluhan ibu sampai waktu itu ibu masuk dan dirawat rumah sakit?
Probes: Kapanakah pertama kalinya ibu mengalami kejadian tersebut? Lalu apa yang dikatakan oleh dokter dan perawat?
- 2. Apakah yang Ibu ketahui tentang penyakit ibu?
- 3. Setelah pertamakali mengalami sakit tersebut, apa yang terjadi dalam hidup ibu?
Probes: Apakah yang berubah sebelum dan sesudah ibu masuk dan dirawat di rumah sakit? Apakah yang dokter atau perawat anjurkan untuk ibu saat ibu diperbolehkan untuk pulang?
- 4. Apakah yang ibu ketahui tentang program rehabilitasi jantung?
Probes: Apakah keuntungan mengikuti program ini? Apakah kerugian mengikuti program ini?
- 5. Secara pribadi, apa alasan/motivasi ibu mengikuti program rehabilitasi jantung ini?
- 6. Bagaimana pada akhirnya ibu memutuskan untuk mengikuti (tidak mengikuti) program rehabilitasi jantung ini?
Probes: Kapanakah Ibu memutuskan untuk mengikuti program rehabilitasi ini? Siapakah yang paling berperan dalam proses pengambilan keputusan ini (apakah atas inisiatif ibu sendiri atautkah karena dorongan dari yang lain)?
- 7. Bagaimana dengan dukungan dari keluarga dan teman-teman/keluarga besar ibu?
 - a. Bentuk bantuan/dukungan apa sajakah yang berguna bagi Ibu untuk mengikuti program rehabilitasi ini?
 - b. Siapakah yang paling banyak membantu ibu selama ini dan mengapa?
- 8. Apa saja kesulitan yang ibu hadapi saat akan dan sedang mengikuti program rehabilitasi ini?

Probes: Bagaimana mengatasinya?

9. Apakah perubahan positif dan negative yang ibu rasakan setelah ibu mengikuti (tidak mengikuti) program rehabilitasi ini?
10. Dapatkah Ibu ceritakan kepada saya tentang bagaimana keseharian Ibu di rumah selama ini?
Probes: Bagaimana kebiasaan di rumah sejak bangun tidur sampai malam hari? Adakah yang berubah sebelum dan sesudah sakit? Bagaimana pembagian tugas rumah tangga di rumah?
11. Siapakah orang yang paling penting (paling berarti) dalam kehidupan ibu? Mengapa?
12. Menurut ibu, siapakah orang yang membuat ibu menjadi diri ibu yang sekarang ini? Bagaimana hal itu bisa terjadi?
13. Bisakah ibu ceritakan apa saja hal-hal yang menjadi prioritas utama (yang diutamakan) dalam kehidupan sehari-hari ibu?
 - a. Apa alasannya?
14. Tolong ceritakan kepada saya bagaimana Ibu menggambarkan/melihat diri Ibu yang sekarang?
Probe: Perannya di keluarga dengan kondisi kesehatan yang sekarang? Bagaimana perasaan ibu dengan kondisi tersebut? Dimanakah Ibu melihat diri Ibu dalam dua tahun mendatang?
15. Apa hikmah yang ibu peroleh dari kejadian ini?
16. Apakah nasehat yang ingin ibu sampaikan untuk orang-orang yang baru akan mulai mengikuti program rehabilitasi?
17. Apakah harapan Ibu dari program rehabilitasi ini?

Ya kiranya ini bincang-bincang kita hari ini ibu. Sebelum kita akhiri apakah ada hal lain yang ingin ibu sampaikan?